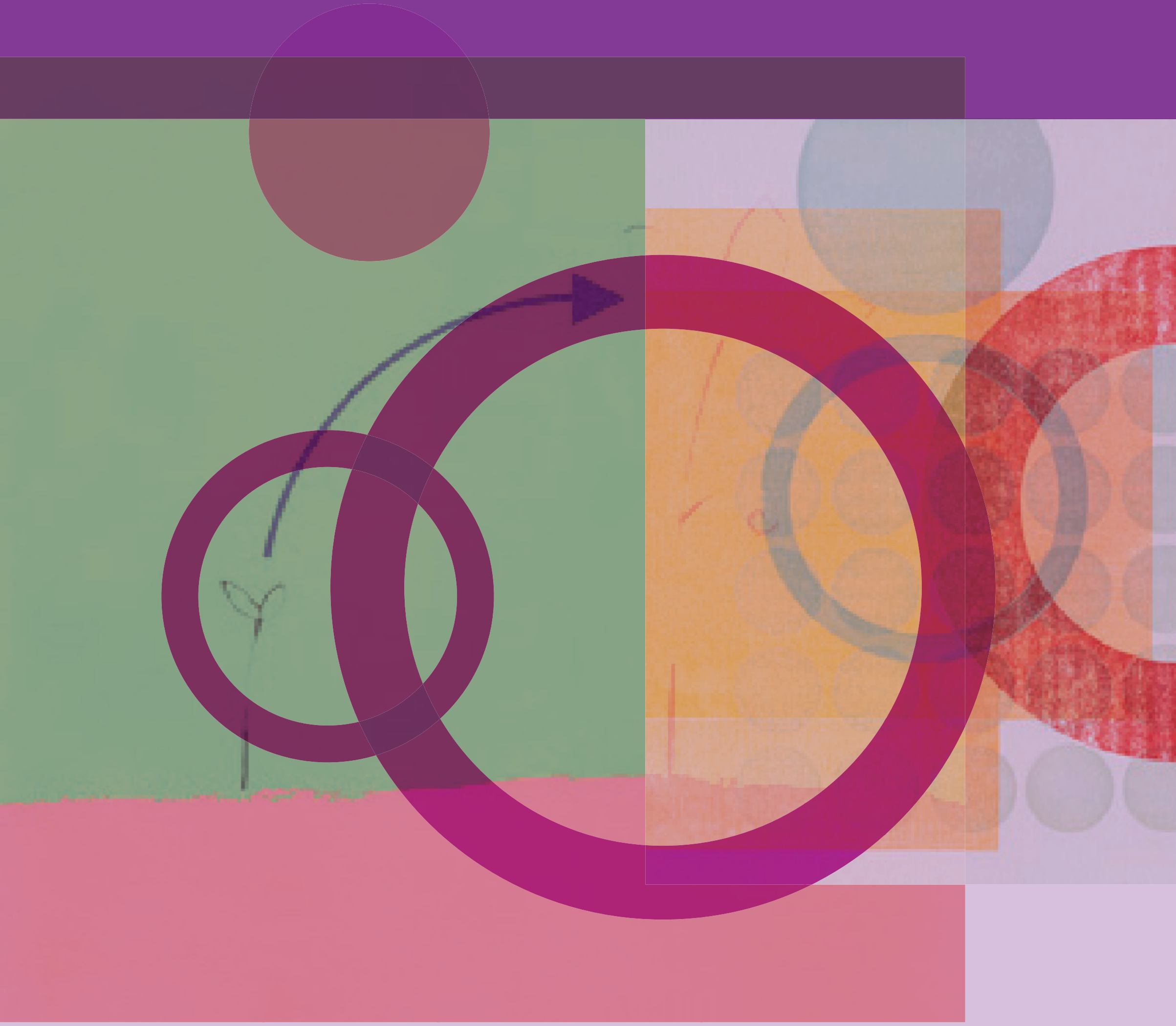
Prevention of disabilities linked to chronic diseases



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Prevention of disabilities linked to chronic diseases

Report drawn up by the Committee of Experts
on the Prevention of Disabilities linked to Chronic Diseases
(P-RR-PREV)

and

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Integration of people with disabilities

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We, the Ministers responsible for integration policies for people with disabilities, gathered from 7-8 May 2003 in Malaga on invitation of the Spanish Government, at the Second European Conference of Ministers, organised by the Council of Europe, consider that it is a basic objective to develop economic, social, educative, employment, environmental and health measures in order to maintain every disabled individual's maximum capacity over the life course and in order to help prevent disability.

Malaga Ministerial Declaration on People with disabilities: "Progressing towards full participation as citizens", paragraph 21.

PART I –
BACKGROUND INFORMATION

Chapter 1 – Right to protection of health

1.1. Introduction

This report outlines international and national policy on the prevention of disabilities and on health education in relation to Council of Europe Recommendation No. R (92) 6 on a coherent policy for people with disabilities. This coherent policy stipulates measures to be taken by member states in the field of prevention of impairment, prevention of disability, prevention of handicap, as well as in the field of health education. As a result of this broad scope of prevention, this report goes beyond health care and people with disabilities as such.

The overall aim of a health strategy is to improve the health of the population, and therefore to improve the quality of their lives. Emphasis on prevention, early treatment and diagnosis is needed to achieve this end. However, this medical approach alone is not sufficient as health is more than the absence of disease or impairment. According to the World Health Organization (WHO) health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.

Within the framework of a coherent policy for people with disabilities, health education of individuals, the community, society and those members of society responsible for decision-making and management is an effective and indispensable preventive instrument. A more modern approach to health education is health promotion. Whereas education implies people being told what to do, health promotion should aim at helping people to develop the ability to take reasonable decisions regarding their own health and comprise all information and educational activities to encourage them to lead a healthy life, to learn what to do to remain in good health, and to avail themselves of social and medical assistance in case of need.

Enabling people to increase control over, and to improve, their health is the approach taken in international policy. People should be regarded as active and responsible citizens and not merely patients or subjects. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being. The prerequisites and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands co-ordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organisations, by local authorities, by industry and by the media.

People in all walks of life are involved as individuals, families and communities. Professional and social groups and health personnel have a major responsibility to mediate between differing interests in society for the pursuit of health. But above all, it remains the individual's responsibility to protect his/her health and to increase the quality of his/her life. Besides having a fundamental right to health, people have the freedom to choose.

Chapter 1 of this report describes a few rights in relation to health and quality of life, as stipulated in instruments of the World Health Organization, the Council of Europe, the European Union and the United Nations, as well as definitions of disability and prevention as used by the World Health Organization, the Council of Europe and the United Nations. Chapter 2 gives an overview of relevant political instruments of the Council of Europe in the field of human rights, health and people with disabilities. Chapters 3 and 4 deal with policy instruments of the World Health Organization, the International Labour Organization, the United Nations and the European Union. Chapter 5 gives an overview of national policy and legislation in the field of prevention and health education, whereas Chapter 6 describes the trends in international and national policy and makes recommendations for future action.

1.2. Rights related to health

1.2.1. Constitution of the World Health Organization

Principles of the World Health Organization as defined in the preamble of its Constitution:

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.
- The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.
- The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and states.
- The achievement of any state in the promotion and protection of health is of value to all.
- Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.
- Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.
- The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.

- Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.
- Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

1.2.2. European Social Charter (1961)

The European Social Charter is the counterpart to the European Convention on Human Rights in the field of economic and social rights. It sets out rights and freedoms and establishes a supervisory mechanism based on reports and collective complaints, guaranteeing their respect by the States Parties. It was recently revised, and the 1996 Revised European Social Charter, which came into force in 1999, is gradually replacing the initial 1961 treaty. The Charter and Revised Charter guarantee a wide range of rights, relating to housing, health, education, employment, social protection, movement of persons and non-discrimination.

Article 3 – The right to safe and healthy working conditions

With a view to ensuring the effective exercise of the right to safe and healthy working conditions, the Contracting Parties undertake:

1. to issue safety and health regulations;
2. to provide for the enforcement of such regulations by measures of supervision;
3. to consult, as appropriate, employers' and workers' organisations on measures intended to improve industrial safety and health.

Article 11 – The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed *inter alia:*

1. to remove as far as possible the causes of ill-health;

2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. to prevent as far as possible epidemic, endemic and other diseases.

Article 12 – The right to social security

With a view to ensuring the effective exercise of the right to social security, the Contracting Parties undertake:

1. to establish or maintain a system of social security;
2. to maintain the social security system at a satisfactory level at least equal to that required for ratification of International Labour Convention (No. 102) Concerning Minimum Standards of Social Security;
3. to endeavour to raise progressively the system of social security to a higher level;
4. to take steps, by the conclusion of appropriate bilateral and multilateral agreements, or by other means, and subject to the conditions laid down in such agreements, in order to ensure:
    a. equal treatment with their own nationals of the nationals of other Contracting Parties in respect of social security rights, including the retention of benefits arising out of social security legislation, whatever movements the persons protected may undertake between the territories of the Contracting Parties;
    b. the granting, maintenance and resumption of social security rights by such means as the accumulation of insurance or employment periods completed under the legislation of each of the Contracting Parties.

Article 13 – The right to social and medical assistance

With a view to ensuring the effective exercise of the right to social and medical assistance, the Contracting Parties undertake:

1. to ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition;
2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights;
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want;
4. to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Contracting Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11 December1953.

Article 14 – The right to benefit from social welfare services

With a view to ensuring the effective exercise of the right to benefit from social welfare services, the Contracting Parties undertake:

1. to promote or provide services which, by using methods of social work, would contribute to the welfare and development of both individuals and groups in the community, and to their adjustment to the social environment;
2. to encourage the participation of individuals and voluntary or other organisations in the establishment and maintenance of such services.

Article 15 – The right of physically or mentally disabled persons to vocational training, rehabilitation and social resettlement

With a view to ensuring the effective exercise of the right of the physically or mentally disabled to vocational training, rehabilitation and resettlement, the Contracting Parties undertake:

1. to take adequate measures for the provision of training facilities, including, where necessary, specialised institutions, public or private;
2. to take adequate measures for the placing of disabled persons in employment, such as specialised placing services, facilities for sheltered employment and measures to encourage employers to admit disabled persons to employment.

1.2.3. Revised European Social Charter (1996)

Article 3 – The right to safe and healthy working conditions

With a view to ensuring the effective exercise of the right to safe and healthy working conditions, the Parties undertake, in consultation with employers' and workers' organisations:

1. to formulate, implement and periodically review a coherent national policy on occupational safety, occupational health and the working environment. The primary aim of this policy shall be to improve occupational safety and health and to prevent accidents and injury to health arising out of, linked with or occurring in the course of work, particularly by minimising the causes of hazards inherent in the working environment;
2. to issue safety and health regulations;
3. to provide for the enforcement of such regulations by measures of supervision;
4. to promote the progressive development of occupational health services for all workers with essentially preventive and advisory functions.

Article 11 – The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed inter alia:

1. to remove as far as possible the causes of ill-health;
2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

Article 12 – The right to social security

With a view to ensuring the effective exercise of the right to social security, the Parties undertake:

1. to establish or maintain a system of social security;
2. to maintain the social security system at a satisfactory level at least equal to that necessary for the ratification of the European Code of Social Security;
3. to endeavour to raise progressively the system of social security to a higher level;
4. to take steps, by the conclusion of appropriate bilateral and multilateral agreements or by other means, and subject to the conditions laid down in such agreements, in order to ensure:
    a. equal treatment with their own nationals of the nationals of other Parties in respect of social security rights, including the retention of benefits arising out of social security legislation, whatever movements the persons protected may undertake between the territories of the Parties;
    b. the granting, maintenance and resumption of social security rights by such means as the accumulation of insurance or employment periods completed under the legislation of each of the Parties.

Article 13 – The right to social and medical assistance

With a view to ensuring the effective exercise of the right to social and medical assistance, the Parties undertake:

1. to ensure that any person who is without adequate resources and who is unable to secure such resources

either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition;

2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights;
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want;
4. to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11 December 1953.

Article 14 – The right to benefit from social welfare services

With a view to ensuring the effective exercise of the right to benefit from social welfare services, the Parties undertake:

1. to promote or provide services which, by using methods of social work, would contribute to the welfare and development of both individuals and groups in the community, and to their adjustment to the social environment;
2. to encourage the participation of individuals and voluntary or other organisations in the establishment and maintenance of such services.

Article 15 – The right of persons with disabilities to independence, social integration and participation in the life of the community

With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

1. to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;
2. to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;
3. to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.

Article 23 – The right of elderly persons to social protection

With a view to ensuring the effective exercise of the right of elderly persons to social protection, the Parties undertake to adopt or encourage, either directly or in co-operation with public or private organisations, appropriate measures designed in particular:

- to enable elderly persons to remain full members of society for as long as possible, by means of:
    - *a*. adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life;
    - *b*. provision of information about services and facilities available for elderly persons and their opportunities to make use of them;
- to enable elderly persons to choose their life-style freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of:

  - *a*. provision of housing suited to their needs and their state of health or of adequate support for adapting their housing;
  - *b*. the health care and the services necessitated by their state;
- to guarantee elderly persons living in institutions appropriate support, while respecting their privacy, and participation in decisions concerning living conditions in the institution.

The control mechanism of the European Social Charter

European Committee of Social Rights

The European Committee of Social Rights (referred to below as "the Committee") ascertains whether countries have honoured the undertakings set out in the Charter. Its thirteen independent, impartial members are elected by the Council of Europe Committee of Ministers for a period of six years, renewable once. The Committee decides whether or not national law and practice in the States Parties are in conformity with the Charter and Revised Charter.

Monitoring procedure based on national reports

Every year the States Parties submit a report indicating how they implement the Charter in law and in practice. Each report concerns some of the accepted provisions of the Charter or Revised Charter. The Committee examines the reports and decides whether or not the situations in the countries concerned are in conformity with the Charter or Revised Charter. Its decisions, known as "conclusions", are published every year. If a state takes no action on a Committee decision to the effect that it does not comply with the Charter or Revised Charter, the Committee of Ministers may address a recommendation to that state, asking it to change the situation in law or in practice. The Committee of Ministers' decisions are prepared by a Governmental Committee comprising representatives of the governments of the States Parties to the

Charter and Revised Charter, assisted by observers representing European employers' organisations and trade unions.

Collective complaints procedure

Under Protocol 3, opened for signature in 1995, which came into force in 1998, complaints of violations of the Charter and Revised Charter may be lodged with the European Committee of Social Rights.[1]

Organisations entitled to lodge complaints with the Committee

In the case of all states that have accepted the procedure:

1. the European Trade Union Confederation (ETUC), Union of Industrial and Employers' Confederations of Europe (UNICE) and International Organisation of Employers;
2. Non-governmental organisations (NGOs) with consultative status with the Council of Europe which are on a list drawn up for this purpose by the Governmental Committee;
3. Employers' organisations and trade unions in the country concerned;

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[1] Complaint No. 14/2003 International Federation for Human Rights (IFHR) v. France.

The complainant organisation alleges that recent reforms of the «Aide médicale de l'Etat» (State medical assistance) and to the «Couverture maladie universelle» (Universal sickness cover) violate Articles 13 (The Right to social and medical assistance), 17 (The Right of the family to social, legal and economic protection) as well as Article E of the Revised Social Charter (prohibition of all forms of discrimination in the application of the rights guaranteed by the treaty). According to the organisation, the reforms in question deprive a large number of adults and children with insufficient resources of the right to medical assistance. The European Committee of Social Rights declared the complaint admissible on 16 May 2003.

Complaint No. 13/2002 Autisme-Europe v. France

The complaint, lodged on 27 July 2002, relates to Article 15 (right of persons with disabilities), Article 17 (right of children and young persons to social, legal and economic protection), and to Article E (non-discrimination) of the Revised Charter. (continued on p. 20)

It alleges insufficient educational provision for autistic persons constituting a violation of the above provisions. The European Committee of Social Rights declared the complaint admissible on 12 December 2002.

In the case of states which have also agreed to this:

4. National NGOs.

The Committee examines the complaint and, if the formal requirements have been met, declares it admissible. Once the complaint has been declared admissible, a written procedure is set in motion, with an exchange of memorials between the parties. The Committee may decide to hold a public hearing. The Committee then takes a decision on the merits of the complaint, which it forwards to the parties concerned and the Committee of Ministers in a report, which is made public within four months of its being forwarded. Finally, the Committee of Ministers adopts a resolution. If appropriate, it may recommend that the state concerned take specific measures to bring the situation into conformity with the Charter or Revised Charter.

1.2.4. Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine (1997)

Article 3 – Equitable access to health care

Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

1.2.5. Charter of Fundamental Rights of the European Union (2000)

Article 25 – The rights of the elderly

The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.

Article 26 – Integration of persons with disabilities

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

Article 31 – Fair and just working conditions

1. Every worker has the right to working conditions which respect his or her health, safety and dignity.
2. Every worker has the right to limitation of maximum working hours, to daily and weekly rest periods and to an annual period of paid leave.

Article 32 – Prohibition of child labour and protection of young people at work

The employment of children is prohibited. The minimum age of admission to employment may not be lower than the minimum school-leaving age, without prejudice to such rules as may be more favourable to young people and except for limited derogations.

Young people admitted to work must have working conditions appropriate to their age and be protected against economic exploitation and any work likely to harm their safety, health or physical, mental, moral or social development or to interfere with their education.

Article 35 – Health care

Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

1.2.6. Universal Declaration of Human Rights (1948)

Article 3

Everyone has the right to life, liberty and security of person.

Article 25

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family,

including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

1.2.7. Convention on the Rights of the Child (1989)

Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

Article 23

1. States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.
2. States Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for

which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognising the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.
4. States Parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
   - *a.* To diminish infant and child mortality;

b. To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;

c. To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;

d. To ensure appropriate pre-natal and post-natal health care for mothers;

e. To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;

f. To develop preventive health care, guidance for parents and family planning education and services.

3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.

4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realisation of the right recognised in the present article. In this regard, particular account shall be taken of the needs of developing countries.

Article 25

States Parties recognise the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

Article 26

1. States Parties shall recognise for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realisation of this right in accordance with their national law.
2. The benefits should, where appropriate, be granted, taking into account the resources and the circumstances of the child and persons having responsibility for the maintenance of the child, as well as any other consideration relevant to an application for benefits made by or on behalf of the child.

Article 27

1. States Parties recognise the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development.
2. The parent(s) or others responsible for the child have the primary responsibility to secure, within their abilities and financial capacities, the conditions of living necessary for the child's development.
3. States Parties, in accordance with national conditions and within their means, shall take appropriate measures to assist parents and others responsible for the child to implement this right and shall in case of need provide material assistance and support programmes, particularly with regard to nutrition, clothing and housing.
4. States Parties shall take all appropriate measures to secure the recovery of maintenance for the child from the parents or other persons having financial responsibility for the child, both within the State Party and from abroad. In particular, where the person having financial responsibility for the child lives in a State different from that of the child, States Parties shall promote the accession to international agreements or the conclusion of such agreements, as well as the making of other appropriate arrangements.

Article 39

States Parties shall take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of: any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child.

1.3. Definitions of disability and prevention

1.3.1. International Classification of Impairments, Disabilities, and Handicaps (ICIDH), WHO, 1980

Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

1.3.2. International Classification of Functioning, Disability and Health (ICF), WHO, 2001

Impairment: a problem in body function or structure such as significant deviation or loss. (Body functions are the physiological functions of body systems, including psychological functions. Body structures are anatomical parts of the body such as organs, limbs and their components.)

(Positive aspect: *body function*)

Activity limitation*: a difficulty an individual may have in executing activities. (Activity is the execution of a task or action by an individual.)

(Positive aspect: *activity*)

Participation restriction**: a problem an individual may experience in involvement in life situations. (Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.)

(Positive aspect: *participation*)

Disability is conceptualised as being a multi-dimensional experience for the person involved. There may be effects on organs or body parts, for example impairment of the structure and/or function of the ear. There may be effects on certain activities such as understanding and producing messages. There may be effects on a person's participation in areas of human life such as education and work or leisure; participation may be facilitated in various ways, for instance by the provision of assistive technology or sign language interpretation.

Correspondingly, three components of disability are recognised in the ICF: body structure and function (and impairment thereof); activity (and activity limitations); and participation (and participation restriction). The classification also explicitly recognises the role of physical and social environmental factors in affecting disability outcomes.

Disability arises when any or all of the negative outcomes occur – impairment, activity limitation and/or participation restriction – when they are associated with a related 'health condition';[1] while restrictions in participation may occur for reasons other than a

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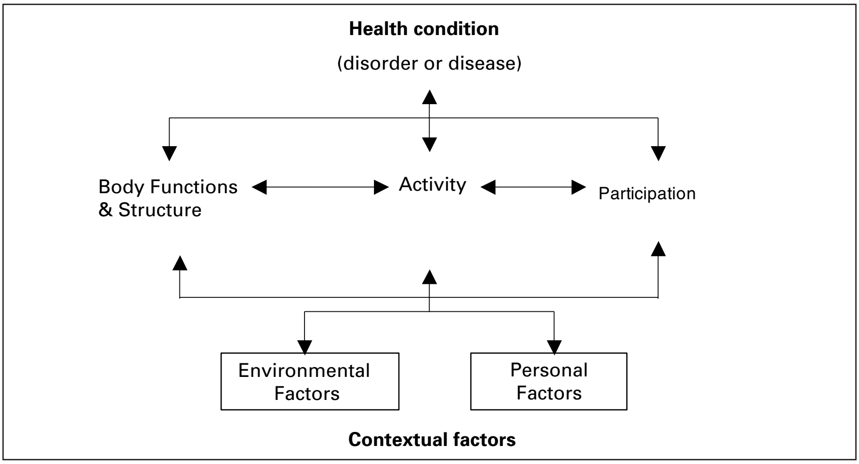
* Activity limitation replaces the "disability" used in the 1980 version of the ICIDH.

** Participation restriction replaces the "handicap" used in the 1980 version of the ICIDH.

[1] A health condition is an alteration or attribute of the health state of an individual that may lead to distress, interference with daily activities, or contact with health services; it may be a disease (acute or chronic), disorder, injury or trauma, or reflect other health-related states such as pregnancy, ageing, stress, congenital anomaly or genetic predisposition' (WHO, 1999).

health-related condition, these restrictions are not considered to be included in the scope of 'disability'. In the WHO Family of International Classifications, health conditions are classified in the International Classification of Diseases, Tenth Revision (ICD-10).

The following diagram is one representation of the model of disability that is the basis for ICF.



The next chart indicates how the different levels of disability are linked to three different levels of intervention.

	Intervention	**Prevention**
Health condition	Medical treatment/care Medication	Health promotion Nutrition Immunisation
Impairment	Medical treatment/care Medication Surgery	Prevention of the development of further activity limitations
Activity limitation	Assistive devices Personal assistance Rehabilitation therapy	Preventative rehabilitation Prevention of the development of participation restrictions
Participation restriction	Accommodation Public education Anti-discrimination law Universal design	Environmental change Employment strategies Accessible services Universal design Lobbying for change

1.3.3. World Health Organization

WHO publication 1995

In the WHO's document "Disability prevention and rehabilitation in primary health care – a guide for district health and rehabilitation managers" (1995), the terms primary, secondary and tertiary prevention of disabilities are clarified as follows.

Primary prevention consists of measures to prevent diseases, injuries, or conditions that can result in impairments or disabilities. Such measures include health education, immunisation, maternal and child health services, and safety promotion. Together they comprise a major component of primary health care. District-level health care personnel are familiar with most primary prevention measures, although they may not have analysed which of these are particularly important in disability prevention.

Secondary prevention consists of early intervention in the treatment of diseases, injuries, or conditions to prevent the development of impairments. Treatment of diseases (such as tuberculosis, onchocerciasis and diabetes) and injuries (such as burns or fractures) may prevent impairments and hence disabilities. Treatment of this type is usually initiated by the referral services, but follow-up is provided within the public health care system. As with primary prevention, the health care staff may not have analysed which treatments are particularly related to disability prevention.

Tertiary prevention includes all measures to limit or reduce impairments or disabilities. It includes, for example, surgery to correct joint deformities and the provision of eye glasses for visual impairments or hearing aids for hearing impairments. In many instances, the treatment will reduce the impairment, as in the surgical correction of deformities. It may also reduce or even eliminate the disabilities that can result from impairments. Tertiary prevention also includes the treatment of disabilities, or rehabilitation. Rehabilitation is the process whereby disability is minimised or eliminated. The rehabilitation process may include training in self-care, communication, or mobility. It may also include training to develop work skills.

WHO publication 1996

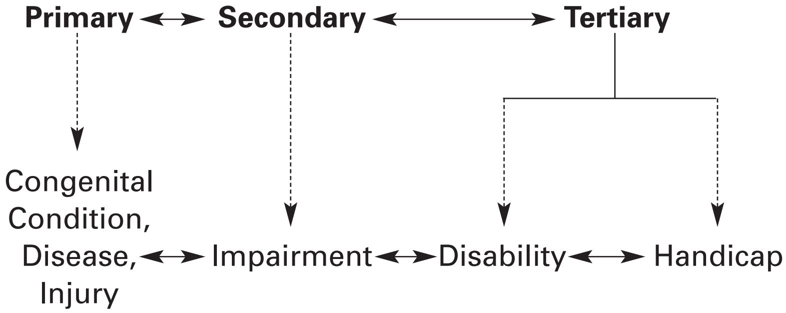
In the WHO's document "Disability prevention and rehabilitation – a guide for strengthening the basic nursing curriculum" (1996), the terms primary, secondary and tertiary prevention of disabilities are defined as follows.

Primary prevention: measures which prevent diseases, injuries or congenital conditions which can result in disabilities.

Secondary prevention: treatments used for diseases, injuries or conditions which could cause impairments.

Tertiary prevention: all measures aimed at the reduction or elimination of impairments, disabilities and handicaps.

The relationship between the levels of prevention and the occurrence of impairments, disabilities and handicaps is illustrated below:



According to the WHO, rehabilitation is generally considered to be the component of tertiary prevention which focuses on the reduction or elimination of a disability. Measures used to assist people with disabilities to improve their abilities in activities such as self-care, communication, moving around, behaving according to social norms or developing vocational skills, are generally considered to be rehabilitative measures.

1.3.4. Council of Europe

Recommendation No. R (92) 6 of the Committee of Ministers to member states on a Coherent Policy for people with disabilities follows the definitions of "impairment", "disability" and "handicap" as established in the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published by the World Health Organization in 1980.

In Recommendation No. R (92) 6, the Council of Europe defines prevention as threefold:

1. **Prevention of impairment:** to prevent an impairment from arising or worsening.
2. **Prevention of disability:** to reduce as far as possible the degree of disability for a given impairment.
3. **Prevention of handicap:** to reduce any social disadvantage arising from a given disability.

According to the Council of Europe report on Use and usefulness of the ICIDH for policy and planning of public authorities (1995), the use of the ICIDH for policy is particularly meaningful when used to formulate prevention-focused policy. ICIDH-based prevention policy gives a good opportunity to evaluate the effect of policy measures. The report recommends that the formulation of rehabilitation policy objectives in terms of prevention-stimulating measures, thus showing that the government has a task in:

- preventing an impairment from arising or worsening;
- preventing disabilities from arising or worsening;
- preventing social disadvantages/handicaps from arising or worsening.

The report recommends furthermore that the relevant public authorities of member states be encouraged to formulate their policy in the way outlined above.

Recommendation No. R (92) 6 recommends the following prevention measures.

Prevention of impairment

To act against direct or indirect causes of impairments:

- action for the prevention of accidents (occurring, for instance, in the home, on the roads, on the sports field, at school and at work);
- action for the prevention of diseases (including occupational diseases, diseases associated with leisure activities, diseases common with elderly people, etc.).

This action should comprise monitoring at various stages during the period of growth, regular check-ups for workers at risk, immunisation, and monitoring of degenerative diseases.

To prevent congenital impairments, services should be set up to provide:

- genetic screening;
- pre-marital screening and diagnosis;
- monitoring of high-risk and normal pregnancies and confinements;
- care for high-risk new-born babies;
- early detection and diagnosis of diseases as well as mental, motor and sensory disorders.

Prevention of disability

In addition to the measures to detect, treat and diagnose impairments at an early stage:

- individualised and community programmes of rehabilitation, including follow-up and evaluation;
- support to individuals and their families.

Prevention of handicap

Along with the steps recommended to prevent impairment and/or disability:

- individualised programmes of psycho-social rehabilitation aiming at the full development of the person;
- provision of information, so as to promote the full integration of people with disabilities into society.

Health education

Educational action intended to prevent impairment should be aimed at the whole population, and primarily at young people of school age, i.e. at a time when children from all backgrounds are still particularly open and amenable to the reception of simple but effective messages concerning health education. Action in regard to specific problems should be aimed at certain specific groups such as women of child-bearing age, couples, drivers and the elderly. Consequently, the information which has to be given should relate to factors and circumstances which may give rise to impairment.

Where there is an impairment, health education may be useful to prevent or limit a disability. The educational action should be aimed at the people suffering from the impairment, their families and all those – the general public as well as professional staff – who may be concerned.

Health education directed to prevent impairments or disabilities from becoming handicaps extends to the whole of society and may promote the concepts of integration and rehabilitation, of equality of opportunity and of participation for people with disabilities.

1.3.5. United Nations

The following definitions are developed from the perspective in the World Programme of Action Concerning Disabled Persons where the United Nations follow the definitions of "impairment", "disability" and "handicap" as established in the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published by the World Health Organization in 1980:

Prevention is any measure aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment, when it has occurred, from having negative physical, psychological and social consequences (secondary prevention). Prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunisation campaigns against communicable diseases, measures to control endemic diseases, safety regulations, programmes for the prevention of accidents in different environments, including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Rehabilitation is a goal-oriented and time-limited process aimed at enabling an impaired person to reach the optimum mental, physical and/or social functional level, thus providing the individual with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example, by technical aids) and other measures intended to facilitate social adjustment or readjustment.

Equalisation of opportunities is the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.

Prevention and rehabilitation, then, relate to an individual's particular attributes (or lack thereof) and may entail special needs. Equalisation relates to the process of building a suitable environment to reasonably accommodate those needs.

Chapter 2 – Council of Europe

2.1. Recommendation No. R (92) 6 of the Committee of Ministers to member states on a coherent policy for people with disabilities

2.1.1. Historical background

The Partial Agreement in the Social and Public Health field was concluded in 1959 by seven member states with the aim of continuing the work in this field previously undertaken under the Brussels Treaty Organisation and then by the Western European Union (WEU). At present, the Partial Agreement has 18 member states;[1] 9 states are observers in the field of integration of people with disabilities.[2]

At the ad hoc Conference of Ministers responsible for Policies on People with Disabilities on 7 and 8 November 1991 in Paris (France), the Ministers responsible for policies on people with disabilities unanimously affirmed the need to adopt a coherent policy with precise objectives, i.e. a comprehensive policy covering all aspects of life and taking account of every stage in an individual's development. The Ministers also agreed that the concept of autonomy for people with disabilities presupposed their full participation in social life and the recognition of their right to independence.

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1. Member states: Austria, Belgium, Bulgaria (as from 1/11/05), Cyprus, (Denmark, until 31/12/05), Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, United Kingdom.
2. Observers: Estonia, Hungary, Iceland, Latvia, Lithuania, Poland, Romania, Russian Federation (as from June 2006) and Canada.

In the final declaration of the conference, the Ministers decided to support a coherent policy for people with disabilities and request the Committee of Ministers to approve the proposal of the Committee on the Rehabilitation and Integration of People with Disabilities (Partial Agreement) (CD-P-RR) as a model text. This text was adopted as Recommendation No. R (92) 6 by the Committee of Ministers (all member states) on 9 April 1992 at the 474th meeting of the Ministers' Deputies.

2.1.2. Goals and methods of rehabilitation

The goals of rehabilitation are to give people with disabilities, whatever the nature and origin of their disability, the greatest possible measure of social and economic participation as well as independence.

National programmes and legislation relating to rehabilitation should place more emphasis on prevention of, and early intervention on, impairments, disabilities and handicaps and the means to permit full participation by the person with a disability in the process of rehabilitation. These programmes should take into account both endogenous and exogenous factors affecting the individual as well as his/her disability.

The aim of prevention is to eliminate the risk or limit the effect of an impairment or disability. Early identification on a systematic basis, whether compulsory or voluntary, in accordance with current practices in member states, offers two advantages:

- to remove or combat the cause or causes of the ailment or impairment as soon as they appear;
- to allow an early start to be made on rehabilitating those concerned.

Medical rehabilitation is an essential stage in the rehabilitation process, and must be closely co-ordinated with educational, occupational and other measures which are part of the process. Medical rehabilitation is based on a detailed diagnosis, which should take place as early as possible, and a whole range of specialised treatment and reliable techniques.

Making the general public aware of the situation facing people with disabilities by means of information and consciousness-raising campaigns about rehabilitation has the twofold effect of imparting knowledge about the difficulties people with disabilities face concerning their potential abilities, and enlisting public support for the efforts made to further rehabilitation and integration.

Integration demands that the general public, teachers, the social partners, and others, particularly the family of the person with a disability, play an increasingly important part in backing up by their own efforts those made by the person with a disability. The role of the family is particularly important and appropriate aid should be made available to any family caring for a person with a disability.

2.1.3. Chapter II of Recommendation No. R (92) 6 on prevention and health education

Aims

Preventive action should be taken as early as possible in the individual, medical, occupational and social spheres as well as in the improvement of the surroundings:

- to prevent an impairment from arising or worsening,
- to reduce as far as possible the degree of disability for a given impairment,
- to reduce any social disadvantage arising from a given disability.

Prevention of impairment

To act against direct or indirect causes of impairments, strategies should be devised for appropriate action for the prevention of accidents (occurring, for instance, in the home, on the roads, on the sports field, at school and at work) and diseases (including occupational diseases, diseases associated with leisure activities, diseases common with elderly people, etc.). This action should comprise monitoring at various stages during the period of growth, regular check-ups for workers at risk, immunisation, and monitoring of degenerative diseases.

The health services should be capable of providing early diagnosis and treatment of impairments. In this context, the important role played by emergency medicine in the rapid and effective treatment of all health problems caused by accidents and for other reasons should be recognised and adequate financing resources, staff and training should be made available.

To prevent congenital impairments, services should be set up to provide genetic screening, pre-marital screening and diagnosis, monitoring of high-risk and normal pregnancies and confinements, care for high-risk new-born babies and early detection and diagnosis of diseases as well as mental, motor and sensory disorders.

The prevention of congenital impairments must always be in accordance with ethical principles. In particular, pre-natal genetic screening and diagnosis require that couples and pregnant women be fully informed and advised about the possibilities of and the reasons for their use, as well as about the risks they involve. Appropriate genetic counselling must provide pregnant women with full information, on the basis of which they may freely take their decision regarding these tests and must always accompany the pre-natal screening and diagnosis but not involve any compulsion.

Prevention of disability

In addition to the measures to detect, treat and diagnose impairments at an early stage, steps should be taken to ensure individualised and community programmes of rehabilitation, including follow-up and evaluation, as well as the necessary support to individuals and their families. These programmes should take account, inter alia, of each individual's specific situation and problems, with the help of functional diagnosis, in order to prevent any secondary (emotional, cognitive, mental, motor or social) effects of the impairment with the help of early educational measures targeted at the individual and the creation of awareness in the family and the sector of society concerned.

Prevention of handicap

Along with the steps recommended to prevent impairment and/or disability, individualised programmes of psycho-social rehabilitation aiming at the full development of the person should be set up. In addition, all necessary and adequate (also binding) measures should be used, as well as adequate measures to provide information, so as to promote the full integration of people with disabilities into society, inter alia, by means of early integration at school, provision of adapted educational services, integration into ordinary working life, etc, to enable them to live an independent life.

Health education

Health education should aim at helping people to develop the ability to take reasonable decisions regarding their own health and comprise all information and educational activities to encourage them to lead a healthy life, to learn what to do – both individually and collectively – to remain in good health, and to avail themselves of assistance in case of need. Within the framework of a coherent policy for people with disabilities, health education of individuals, the community, society and those members of society responsible for decision-making and management is an effective and indispensable preventive instrument.

Educational action intended to prevent impairment should be aimed at the whole population, and primarily at young people of school age, i.e. at a time when children from all backgrounds are still particularly open and amenable to the reception of simple but effective messages concerning health education.

Action in regard to specific problems should be aimed at certain specific groups such as women of child-bearing age, couples, drivers and the elderly. Consequently, the information which has to be given should relate to factors and circumstances which may give rise to impairment, such as:

- factors which stimulate congenital malformation (chemical, radioactive, biological and pharmacological agents, infection organisms),
- adverse effects on the foetus as well as cerebral lesions,
- growth deficiencies,
- certain pathological conditions,
- risks associated with lifestyles, for instance smoking, drinking,
- the process of ageing and circumstances which are the cause of accidents or which can lead to accidents.

Where there is an impairment, health education may be useful to prevent or limit a disability. The educational action should be aimed at the people suffering from the impairment, their families and all those – the general public as well as professional staff – who may be concerned.

The information to be provided should concern the situations and types of behaviour which give rise to disability, the measures which may be taken, use of the health services and the lifestyle of the individuals and their families. Elderly ill people should be made aware that in many cases their condition is not irreversible if modern medical and psychological measures are applied and the combination of therapeutical measures and personal determination can change their situation.

Health education directed to prevent impairments or disabilities from becoming handicaps extends to the whole of society and may promote the concepts of integration and rehabilitation, of equality of opportunity and of participation for people with disabilities.

Educational action should aim at:

- informing people with disabilities, their families and the general public how and why disability can lead to handicap, and how handicaps may be prevented or limited,

- meeting individuals' needs for independence and personal development in everyday life, work, schooling and recreation,
- contributing to the creation of individual and collective attitudes which can make life easier for people with disabilities,
- and should make it possible to start a dialogue and foster solidarity between people with disabilities and the able-bodied.

2.2. Recommendation No. R (84) 24 of the Committee of Ministers to member states on the contribution of social security to preventive measures

The preamble to the Recommendation No. R (84) 24 says that prevention is vitally important not only to individual health, well-being and fulfilment but also to community welfare. The development and improvement of preventive measures will facilitate social progress in Europe.

In 1984 it was considered that, in view of the humanitarian, social and financial implications of the risks inherent in modern living and working conditions, social security should make a greater contribution to preventive measures, particularly by developing fundamental and applied research in this field, where such measures are not the responsibility of other institutions or bodies.

For the purpose of this recommendation the term "prevention" applies to any measure aimed at preventing the occurrence of a contingency covered by social security.

In the field of health the following measures could be promoted:

- paying particular attention to promoting health, in particular through health education programmes (at school, at work and in the community) because of the positive influence of such education on the contingencies covered by social security. Health education may allow each individual to become aware of the possibilities he has of improving his health or preventing certain diseases and hence of directly influencing his living and working conditions;

- ensuring that preventive examinations are geared more specifically to sections of the populations which are at risk;
- encouraging the development of preventive measures as part of ordinary, and in particular preventive, health care;
- reinforcing medical examinations during pregnancy and improving health and social aid for expectant mothers and mothers on their own;
- facilitating access to health care facilities by reducing or abolishing the proportion of the costs borne by the protected persons, subject to the funds available, notably in the case of serious illness, by developing the third-party-payment system or by promoting prevention-oriented health centres and their satisfactory geographical distribution;
- giving priority to functional and occupational rehabilitation measures for the sick, accident victims and invalids.

In the field of occupational hazards the following measures could be promoted:

- promoting the prevention of occupational injuries and diseases, in particular by informing and advising firms, alerting and training workers and visiting firms;
- encouraging firms to develop and perfect their job safety measures, for instance by financial action (advances to employers), by means of a rating system (adjustment of contribution rates or insurance premiums according to the number of accidents in the firm and to the effort it has made at prevention) or by means of consciousness-raising campaigns;
- assisting with the organisation of occupational health services, with particular reference to Resolution (72) 5 on the harmonisation of measures to protect the health of workers in places of employment.

In the field of old age the following measures could be promoted:

- contributing to the development of measures to prevent and control the consequences of old age and to rehabilitate and compensate the persons concerned, such measures to be based on the aims and measures set out in Resolution (70) 16 on social and medico-social policy for old age;
- promoting preparation-for-retirement measures so as to prevent social, psychological and physiological problems resulting from a sudden transition from working life to retirement, having regard to Resolution (77) 34 on preparation for retirement;
- encouraging appropriate preventive examinations with a view to ensuring that old people remain as active as possible, both physically and mentally.

In the field of family welfare the following measures could be promoted:

- considering the possibility of making the working hours of people bearing direct family responsibilities more flexible, without thereby adversely affecting the social security benefits to which they would be entitled (more part-time work, parental or family leave, shortening of the working week);
- promoting social services to assist families (family aid services, crèches, child-minding centres, social centres).

2.3. Recommendation No. R (86) 5 of the Committee of Ministers to member states on making medical care universally available

The preamble of Recommendation No. R (86) 5 says that the right to the protection of health is an integral part of the human rights whose protection is one of the fundamental principles of the Council of Europe. The recommendation draws inspiration from International Labour Organization

Recommendation No. 69 (1944) concerning medical care, and from its own Recommendation No. R (84) 24 on social security's contribution to preventive measures.

The recommendation makes reference to the provisions of points 11, 12 and 13 of Part I and of Article 11 of the European Social Charter concerning the right of every individual to protection of health as well as those of Articles 12 (the right to social security) and 13 (the right to social and medical assistance).

The recommendation recommends that the governments of member states:

- extend the right to medical care aimed at prevention, cure and rehabilitation to all residents;
- arrange for the necessary health infrastructure to be made available to everyone in their territories;
- take all steps to ensure that the necessary medical care is financially accessible.

Guidelines for the provision of medical care for all residents:

- a protective health care system should be set up, enabling all residents to obtain medical care as a right;
- heath care should aim to preserve, restore or improve the health of the protected persons. It should be made available throughout the contingency, preferably without a qualifying period. Particular attention should be given to preventive measures and to the development of domiciliary and ambulatory care;
- a full range of health services which are easily accessible and effective should be provided;
- taking into account their national circumstances, appropriate measures should be taken to ensure that the quality of the protection offered is not reduced by making care universally available.

2.4. Recommendation No. R (90) 22 of the Committee of Ministers to member states on the protection of the mental health of certain vulnerable groups in society

The Committee of Ministers note in the preamble of Recommendation No. R (90) 22 that in the constitution of the World Health Organization (WHO), health is defined as “a state of complete physical, mental and social well-being” and that the European Health Ministers placed the emphasis on promotion of mental health at their conference in Stockholm in 1985. Furthermore the Committee of Ministers notes the relevance of the World Health Organization’s Targets for Health for All for the European region and of its recent policy documents on prevention of mental, neurological and psycho-social disorders.

The recommendation considers prevalence of mental disease as a major public health problem of growing importance and a serious and costly burden for the individual, the family and the community. Measures to promote mental health amongst vulnerable groups may considerably reduce the incidence of mental disease and the resulting impairment.

The objectives of mental health promotion include:

- promotion of psycho-social skills and coping mechanisms at individual level;
- promotion of supportive networks at interpersonal and social levels;
- promotion of adequate psycho-social services to meet the need;
- promotion of more appropriate living conditions in terms of housing, education, etc. for vulnerable groups.

Measures aimed at reducing the incidence of mental health problems at primary level depend to a large extent on situations outside the normal sphere of health and social services activities. In view of the long duration of mental health problems, early identification and intervention programmes within the secondary and tertiary levels of care is important.

High priority should be given to the promotion of positive mental health for children and adolescents. In this context multidisciplinary groups should be established to advise on policy formation.

Mental health policies for ethnic minorities should be formulated to take account of the needs of immigrants, migrant workers and refugees, and should ensure the involvement of the target group concerned.

Particular attention should be paid to the psycho-social aspects of disasters including the need for laying down guidelines for dealing with the psychological consequences, for those involved (disaster victims and relief workers), of major disasters as recommended by the World Health Organization.

Comprehensive mental health policies for the elderly should be developed which are both community-orientated and multidisciplinary at primary, secondary and tertiary levels.

A review should be carried out of existing research into factors affecting the mental health of these groups and further research should be promoted in the following areas:

- development of healthy coping mechanisms among vulnerable groups;
- the factors which may facilitate satisfactory psycho-social development of children and young people at risk, including those exposed to abuse;
- single parents and their children, bearing in mind changing patterns of family life;
- changing patterns of suicide and parasuicide aimed at identifying effective methods of prevention, with special reference to young adults;
- factors that could affect the mental health of ethnic minorities including immigrants, migrant workers and refugees;

- impact of early retirement on the mental health of elderly people and the risk factors for dementia, cognitive decline and confusion;
- methods of providing support to the families of mentally and physically handicapped people and sufferers from serious or long-term mental disorders, and of making the public aware of their needs.

Improved education and training should be provided in the following areas:

i. therapeutic skills for health and social service professionals:

  a. in the undergraduate curriculum of health, education and social services personnel, in relation to the use of problem-solving approaches for various groups, cultures, and social systems;

  b. at post-graduate level, multidisciplinary training with emphasis upon the formation of self-help groups, the importance of communication and the need for awareness of local community needs;

ii. use of early detection methods by health and social services professionals:

  a. in relation to suicides and parasuicides, promotion of skills in early diagnosis, particularly in relation to depression;

  b. in relation to teenagers with unwanted pregnancies, emphasis on the identification of potential mental health problems;

  c. in relation to school failures and runaways, training for both education and health personnel in the early detection of problems at school, and in multidisciplinary approaches taking account of the educational, psychological and social aspects;

  d. to distinguish normal from pathological bereavement reactions;

iii. coping skills for people belonging to vulnerable groups:
   - *a*. in relation to single parents, who lack adequate financial or social support: promotion of greater awareness of potential mental health problems in the absence of adequate support;
   - *b*. for families at risk in relation to child abuse: training in appropriate patterns of parenting and assistance in establishing improved relationships with their children;
   - *c*. for immigrants: training in the setting up of self-help groups, with educational leaflets being made available in the relevant languages and/or dialects;
   - *d*. for those approaching old age: training in preparation for retirement;
   - *e*. for families of terminal patients: training in coping with the process of dying, and the subsequent period of bereavement.

2.5. Recommendation No. R (91) 2 of the Committee of Ministers to member states on social security for workers without professional status (helpers, persons at home with family responsibilities and voluntary workers)

Recommendation No. R (91) 2 recommends that the governments of member states progressively take the measures needed to ensure that:

- persons working in family businesses without recognised professional status,
- persons at home with family responsibilities for young children, or dependent disabled or old persons, and
- persons doing voluntary work

may enjoy social security protection. Their protection can be realised by derived rights or, more particularly, by the acquisition of personal rights.

With respect to persons at home with family responsibilities for young children, disabled or old persons, the recommendation applies to persons at home devoting themselves in a family context to bringing up young children or caring for dependent disabled or old persons.

All the persons concerned should be covered by the branches of sickness/maternity (benefits in kind), invalidity, old-age and family benefits. Persons who interrupt or delay the start of their occupational activity, for a given period, to exercise family responsibilities in looking after young children or dependent disabled or old persons should be given credit for the period in question, in accordance with prescribed procedures, for the purpose of entitlement to invalidity and old-age benefits, and the calculation of those benefits. Periods of part-time work should be considered as periods of full-time work in order to fulfil the qualifying period required for entitlement to sickness/maternity, old-age and invalidity benefits and family benefit when part-time work is chosen in order to exercise family responsibilities in looking after young children or dependent disabled or old persons. Old-age, invalidity and family benefits should be brought up to the level that full-time occupational activity would give them during the period in question.

Persons who refrain from engaging in an occupational activity to devote themselves for a given period in a family context to bringing up young children or caring for dependent disabled or old persons, should be given credit for the period in question, in accordance with prescribed procedures, for the purpose of entitlement to invalidity and old-age benefits, and the calculation of those benefits. The amount of the benefits should correspond to the standards laid down by the Council of Europe's social security instruments, particularly the European Code of Social Security (revised).

The protection of the persons concerned should be financed:

- either by their own contributions, taking account of their contributory capacity;
- by all the members of the scheme;

- by taxation;

or by a combination of those systems.

2.6. Recommendation 1185 (1992) of the Parliamentary Assembly to the Committee of Ministers on rehabilitation policies for the disabled

In order to give people with disabilities opportunities to be as fully involved as possible in society and working life and to be as independent as possible, the Assembly called on the governments and the agencies concerned in its member states to give priority to *(inter alia):*

a. preventive measures, both genetic and medical, in the light of new scientific discoveries but also of bioethical hazards and restrictions; special attention should be paid to infant mental health and neuro-psychiatry centres because of the crucial effects of any action taken at an age when children are developing;

b. reinforcing home services and assistance to families, with special attention being paid to severely disabled people and dependent elderly people;

c. setting up a network of local and regional rehabilitation and social back-up services, to be run as far as possible by family and voluntary associations;

d. defining European standards for the training of specialised medical and technical personnel, care being taken to avoid confusion between responsibilities and above all to establish that medical diagnosis and treatment be entrusted only to doctors with special training in the field of rehabilitation;

e. supporting every effort aimed:

  - at helping and standing by and improving awareness of the problems of disabled people;
  - at backing charity initiatives;

- at surmounting obstacles, especially those of a psychological character, between disabled people and their families and the rest of society.

The Assembly recommends moreover that the Committee of Ministers:

i. seek to associate the governments of all member states, and if possible of all European states, in the activities of the Council of Europe for the benefit of people with disabilities, which may be physical, psychological and/or sensorial in origin, and to encourage the holding of periodic conferences of European specialised ministers;

ii. promote the use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) having regard to the work of the Council of Europe within the frame of its Partial Agreement;

iii. invite the government of each member state to describe what steps have been taken to implement Recommendation No. R (92) 6 on a coherent policy for people with disabilities;

iv. to provide for the setting-up of a European information and evaluation system for obtaining reliable statistics, calculated with regularly updated indicators, in order to provide information and forecasts that are comparable from one European country to another.

2.7. Recommendation No. R (94) 11 of the Committee of Ministers to member states on screening as a tool of preventive medicine

The preamble of Recommendation No. R (94) 11 says that chronic diseases are the major causes of death and a high social and economic burden in developed countries. Screening for the early detection of these diseases could, in principle, provide a method for their control.

For the purposes of this recommendation, screening means applying a test to a defined group of persons in order to identify an early stage, a preliminary stage, a risk factor or a combination of risk factors of a disease. In any case it is a question of detecting phenomena, which can be identified prior to the outbreak of the disease. Screening is only one method of controlling disease. It should be viewed in the whole context of reducing the burden of ill-health to the individual and the community by, for example, socio-economic, environmental measures, health education and improvement of existing health care and disease prevention systems.

Screening is a tool which is potentially capable of improving the health of the population but it also has adverse effects. Constant care should be taken to ensure that in any screening programme the advantages prevail over the disadvantages. The general benefits of screening are often described. It is, however, also important to be aware of the adverse effects which can be:

- stigmatisation and/or discrimination of (non) participants;
- social pressure to participate in the screening and undergo the intended treatment/intervention;
- psychological distress where there is no cure for the disease or where the treatment and/or intervention is morally unacceptable to the individual concerned;
- exposure to physical and psychological risks with limited health gains;
- creation of expectations which probably cannot be fulfilled; individuals who are positively screened might experience difficulties such as access to insurance, employment, etc.;
- severe side effects of invasive clinical diagnosis of false positives;
- delay in diagnosing false negatives;
- unfavourable cost-benefit relationship of a screening programme.

The increasing financial burden of health care makes it necessary to assess the economic aspects of screening. However these aspects should not be the overriding consideration. In all screening programmes human consideration regarding the value and quality of life, life expectancy as well as respect for individual rights are of prime importance. Economic assessments are necessary to enable rational decisions to be made on the priority to be given to alternative ways of using health resources.

The recommendation stresses that screening cannot succeed without co-operation between preventive and curative systems. Organisation must be tailored to the structures of the health system. If appropriate structures in the curative health care system are lacking, screening should not be implemented until they are developed (pilot programmes, for example). There are various degrees to which screening services may be integrated with curative services or develop as a separate speciality. The advantages and disadvantages of these should be assessed separately in different health care systems.

2.8. Recommendation No. R (98) 9 of the Committee of Ministers to member states on dependence

The preamble of Recommendation No. R (98) 9 considers that the demographic situation in Europe is characterised by low fertility rates and increasing life expectancy, resulting in an ageing society. People are living longer in good health, while the number of chronic diseases – a potential factor of dependence – is increasing. The traditional family is changing, with the emergence of smaller families and an increasing number of single-parent families, the interdependence between generations is changing and the individual, the family and society will have to adapt to this new situation. Policies concerning old age, disabled persons, health, the family and employment have implications for the approach to be adopted to the problem of dependence.

“Dependence” is defined here as a state in which persons, by reason of lack or loss of physical, psychological or intellectual autonomy, require significant assistance or help in carrying out their usual day-to-day activities. The principle of autonomy for the dependent person must be a guiding factor in every policy concerning dependent persons.

The recommendation makes reference to the texts adopted within the Council of Europe also dealing with aspects of dependence, such as Recommendation No. R (87) 22 of the Committee of Ministers on the screening and surveillance of elderly persons, Recommendation No. R (90) 22 of the Committee of Ministers on the protection of the mental health of certain vulnerable groups of society, Recommendation No. R (91) 2 of the Committee of Ministers on social security for workers without professional status (helpers, persons at home with family responsibilities and voluntary workers), Recommendation No. R (92) 6 of the Committee of Ministers on a coherent policy for people with disabilities and Recommendation No. R (84) 24 of the Committee of Ministers on the contribution of social security to preventive measures.

All dependent persons or persons who may become dependent, regardless of their age, race and beliefs and the nature, origin and degree of severity of their condition, should be entitled to the assistance and help required to enable each of them to lead a life as far as possible commensurate with their ability and potential. They should therefore have access to services of good quality and to the most suitable technologies.

All dependent persons are entitled to respect for their human dignity and their autonomy. In this respect they should be involved in the evaluation of their degree of dependence and in any decisions concerning them. This implies, inter alia, that all dependent persons must be informed of their rights, the possible choices and the resources available to them and the state of the relevant legislation.

At the same time, the public authorities have a duty to assume responsibility for dependence by adopting legislative measures in line with scientific and technological developments in this area in order to ensure equality of opportunity and guarantee access to care and services. Public authorities should guarantee the quality of care and services.

Persons concerned by dependence must be treated without discrimination, particularly with regard to access to the infrastructure and services designed for them. Participation of dependent persons in social life, including leisure activities, should be encouraged, and access to such activities should be facilitated by the competent authorities.

In addition to benefits, social protection systems should develop preventive measures, screening and early diagnosis of conditions that could lead to dependence.

Prevention and rehabilitation are fundamental aspects of assuming responsibility for dependence. Preventive action should be taken as early as possible to avoid the occurrence of dependence, to prevent it from worsening and to reduce the extent of dependence as much as possible.

Prevention should be on several levels:

- health education,
- accident prevention,
- detection and diagnosis,
- efficient treatment of causal diseases,
- reduction of the risk arising from isolation.

In addition, optimum rehabilitation must be encouraged given that dependence is not an absolute state but one which evolves, and that it exists in varying degrees. In this context, the principles set out in Recommendation No. R (92) 6 on a coherent policy for the rehabilitation of people with disabilities could be followed.

The principle of non-discrimination on the basis of age is crucial with regard to access to rehabilitation.

Rehabilitation should enable the dependent person to become as independent as possible in psychological, physical and social terms. Multidisciplinary intervention seems to be the best way to achieve this. The measures adopted must be adjusted to variations in the person’s condition. It is essential to encourage ordinary activities and relationships.

Access to the necessary technical aids must be guaranteed.

2.9. Recommendation No. R (98) 11 of the Committee of Ministers to member states on the organisation of health care services for the chronically ill

According to the Committee of Experts a definition of a “chronically ill person” presupposes some degree of disability and/or care dependence in relation to chronic conditions. There is a wide variation in the consequences of chronic conditions for people’s daily functioning, nor are they all extensive users of health care. Some patients are disabled to such an extent that they are fully dependent and need institutional care in nursing homes.

The group of chronically ill persons differs in several respects from the group of handicapped persons. An analytic framework for the discussion of the similarities and differences between both groups could be derived from the ICIDH. The ICIDH provides a key to the analysis of the illness burden of chronic conditions, on the basis of the following model:

Disease → impairment → disability → handicap

The definition of chronically ill persons includes the path from disability to handicap. Chronically ill persons could be considered as handicapped if they are also at a societal disadvantage. Likewise, not all handicapped persons can be regarded as chronically ill, if the handicap is not directly related to chronic diseases.

The recommendation focuses on common issues of the chronically ill in relation to health care, i.e.:

- complications and co-morbidity;

- functional impairments;
- long-term disability;
- psychological distress;
- diminished quality of life.

Strategies aimed at ensuring high quality health care for the chronically ill should, inter alia, strengthen primary and secondary prevention. Primary and secondary prevention are not defined as such. The explanatory memorandum to the recommendation says that "early therapeutic action should be taken to limit the effects of the chronic diseases and to prevent resulting handicaps."

Research should focus on the distribution of chronic diseases, in particular on health inequalities and on effective interventions to diminish these in equalities. These inequalities are related to age (higher prevalence among elderly), gender (higher prevalence among females), socio-economic status (higher prevalence among lower socio-economic groups).

2.10. Recommendation No. R (99) 4 of the Committee of Ministers to member states on principles concerning the legal protection of incapable adults

The following principles apply to the protection of adults who, by reason of an impairment or insufficiency of their personal faculties, are incapable of making, in an autonomous way, decisions concerning any or all of their personal or economic affairs, or understanding, expressing or acting upon such decisions, and who consequently cannot protect their interests. The incapacity may be due to a mental disability, a disease or a similar reason. The principles apply to measures of protection or other legal arrangements enabling such adults to benefit from representation or assistance in relation to those affairs.

In these principles "adult" means a person who is treated as being of full age under the applicable law on capacity in civil matters. In these principles "intervention in the health field" means any act performed professionally on a person for reasons of health. It includes, in particular, interventions for the purposes of preventive care, diagnosis, treatment, rehabilitation or research.

In relation to the protection of incapable adults the fundamental principle, underlying all the other principles, is respect for the dignity of each person as a human being. The laws, procedures and practices relating to the protection of incapable adults shall be based on respect for their human rights and fundamental freedoms, taking into account any qualifications on those rights contained in the relevant international legal instruments.

Where an adult is subject to a measure of protection under which a given intervention in the health field can be carried out only with the authorisation of a body or a person provided for by law, the consent of the adult should nonetheless be sought if he or she has the capacity to give it. Where, according to the law, an adult is not in a position to give free and informed consent to an intervention in the health field, the intervention may nonetheless be carried out if:

- it is for his or her direct benefit, and
- authorisation has been given by his or her representative or by an authority or a person or body provided for by law.

The law should provide for remedies allowing the person concerned to be heard by an independent official body before any important medical intervention is carried out.

Subject to protective conditions prescribed by law, including supervisory, control and appeal procedures, an adult who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.

When, because of an emergency situation, the appropriate consent or authorisation cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the person concerned.

2.11. Recommendation No. R (2000) 5 of the Committee of Ministers to member states on the development of structures for citizen and patient organisation in the decision-making process affecting health care

According to the preamble of Recommendation No. R (2000) 5, participation in the decision-making process will lead to public acceptance of health policy goals. It is considered necessary for each member state to help to broaden the public's general knowledge about health problems, promote healthy living, disease prevention and ways of taking responsibility for their own health.

Empowering citizens revitalises representative democracy, enhances social cohesion, leads to the better functioning of the health care system, and establishes a better balance of interests and a partnership between the various players in the system. Patient empowerment and citizen participation can be achieved only if basic patients' rights are implemented and that, in its turn, patient participation is a tool for the full implementation of these rights in daily practice.

Information on health care and on the mechanisms of the decision-making process should be widely disseminated in order to facilitate participation. It should be easily accessible, timely, easy to understand and relevant. Governments should improve and strengthen their communication and information strategies should be adapted to the population group they address. Regular information campaigns and other methods such as information through telephone hotlines should be used to heighten the public's awareness of patients' rights. Adequate referral systems should be put in place for patients who would like additional information (with regard to their rights and existing enforcement mechanisms).

In Europe, society is making more and more ethical demands. Citizens are calling for more openness and accountability. Movements for the promotion of human rights, civic rights and consumer rights are emerging practically everywhere. In the health sector, citizens are demanding that the population and patients be central to the concerns of health policies and health care. People want unrestricted access to information. Groups are joining forces to ensure there is equal accessibility to health and health care for the most vulnerable sections of the community such as the elderly, the disabled and those in precarious situations.

Patients' movements are growing, and in all countries patients are exerting pressure in order to secure the right to choose their own doctor and are becoming more sensitive to the issue of the quality of health care provided. In addition, recent progress in genetics and the ability to intervene at different stages of life raise considerable ethical issues on which a public debate is essential. The setting up of national ethical commissions is an important progress in this process.

2.12. Recommendation Rec(2000)18 of the Committee of Ministers to member states on criteria for the development of health promotion policies

The Committee of Experts preparing Recommendation Rec(2000)18 viewed health promotion as the promotion of well-being and the prevention (or a reduction in the probability) of disease or ill-health. Health promotion is viewed as consisting of three types of measures: health education, health protection and disease prevention.

A central goal of a strategy is to improve people's health through a reduction in risk factors, and the prevention and postponement of chronic illness. Achieving a shift towards prevention and early diagnosis and treatment offers the greatest potential for the cost effective improvements in health. It must be emphasised, however, that prevention, treatment and care are not alternatives. An aim of a strategy is to find the optimum balance of these activities, both within and outside the health care system.

In order to make informed choices about health promotion programmes, the public, which is the major provider of health and social care, through self-care and care of family and friends, should have free access to information about the range of treatments or policy interventions available, their outcomes and variations in outcomes. Where possible, the existing knowledge and evidence basis should be explained in plain language.

The public should be properly informed about the benefits of health promotion and especially about health protection and disease prevention programmes. They should also be informed about any accompanying risks and harmful effects. The quality criteria should also be made known.

When health promotion and health education programmes are drawn up they should take into account the culture, the traditional beliefs and values of the communities for which they are intended. Information on the effectiveness of health promotion programmes such as the WHO CINDI programme and the European Network of Health Promoting Schools (ENHPS) project (a joint WHO/Council of Europe/European Commission project) should be made more widely available. Local demonstration projects should build on knowledge gained from such projects and demonstrate the real effectiveness and transferability of knowledge to different countries and cultures.

The role of different professional and occupational groups (doctors, nurses, teachers, pharmacists, police, social workers) should be defined (at a countrywide level) and their training adapted and developed as appropriate. Where necessary management and incentive arrangements should be changed to support the provision of health promotion. The specific roles of policy makers in many sectors including that of politicians and the media need to be recognised and supported through information, education and other approaches.

2.13. Resolution ResAP(2001)1 of the Committee of Ministers to member states of the Partial Agreement in the Social and Public Health Field on the introduction of the principles of universal design into the curricula of all occupations working on the built environment

The Committee of Ministers, in its composition restricted to the Representatives of the member states of the Partial Agreement in the Social and Public Health Field, makes reference in the preamble of Resolution ResAP(2001)1 that it bears in mind the Convention for the Protection of Human Rights and Fundamental Freedoms, and in particular the freedom of movement (Article 2 of Protocol No. 4) and the principles embodied in the revised European Social Charter, namely the right of persons with disabilities to independence, social integration and participation in the life of the community, in particular through measures aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure (Article 15, paragraph 3).

The right of all individuals, including persons with disabilities, to full participation in the life of the community involves the right to access to and use and understanding of the built environment. It is the responsibility and duty of society, and in particular of all occupations working on the built environment, to make it universally accessible to everyone, including persons with disabilities.

A coherent and global policy in favour of people with disabilities or who are in danger of acquiring them should aim at, inter alia, guaranteeing full citizenship, equality of opportunity, independent living and active participation in all areas of community life. To implement this policy states should take steps to, inter alia, avoid and remove, wherever possible, all obstacles in the built environment and to improve the information of all policy makers and other stakeholders whose decisions concerning the manmade environment affect the quality of life of people with disabilities.

Such policy includes the education and training of key players in this process. Through a co-ordinated set of measures introducing the concept of universal design into the curricula of all occupations working on the built environment, people of all ages, sizes and abilities should be enabled to have as much mobility and access to buildings, as well as means of transport, as possible, so that they can play a full role in society and take part in economic, social, cultural, leisure, and recreational activities.

"Universal design" is a strategy which aims to make the design and composition of different environments and products accessible and understandable to, as well as usable by, everyone, to the greatest extent in the most independent and natural manner possible, without the need for adaptation or specialised design solutions. The intent of the universal design concept is to simplify life for everyone by making the built environment, products, and communications equally accessible, usable and understandable at little or no extra cost. The universal design concept promotes a shift to more emphasis on user-centred design by following a holistic approach and aiming to accommodate the needs of people of all ages, sizes and abilities, including the changes that people experience over their lifespan. Consequently, universal design is a concept that extends beyond the issues of mere accessibility of buildings for people with disabilities and should become an integrated part of architecture, design and planning of the environment.

2.14. Resolution ResAP(2001)3 of the Committee of Ministers to member states of the Partial Agreement in the Social and Public Health Field towards full citizenship of persons with disabilities through inclusive new technologies

The Committee of Ministers, in its composition restricted to the Representatives of the member states of the Partial

Agreement in the Social and Public Health Field, makes reference in the preamble of Resolution ResAP(2001)3 that it bears in mind the principles embodied in the revised European Social Charter, namely the right of persons with disabilities to independence, social integration and participation in the life of the community, in particular through measures aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure (Article 15, paragraph 3).

Any coherent and global policy should aim at guaranteeing to all individuals full citizenship, equality of opportunity, independent living, freedom of choice, as well as full and active participation in all areas of community life. Since in today's society the possibility of accessing and using technology applications is a prerequisite to achieving the aforementioned aims, it is the responsibility and duty of society to ensure equal access to technology applications for everyone, irrespective of age, gender or ability. To ensure equal chances of full and active participation in the life of the community, everyone should be able to benefit from technology applications and to access and use them as independently and as equally to others as possible, even though specific modifications or solutions might be required sometimes.

Through a co-ordinated set of measures, people of all ages and abilities should be enabled to have as much personal autonomy and independence as possible, so that they can play a full role in society and take part in economic, social, cultural, leisure and recreational activities. Mainstreaming, Design for All and user involvement should be guiding principles in all the public authorities' policy areas.

The following specific principles and the responses to the leading questions will play a decisive role in determining whether persons with disabilities will benefit from the manifold opportunities that new technologies can offer, or whether they will be excluded from that potential by newly-created obstacles. These specific principles and leading questions should be applied now and in future to all products, general services, systems and assistive technology for persons with disabilities in all spheres of life. Policy areas of particular importance are children and education, vocational guidance and training, employment, social integration and environment, the medical field, research and development and training of persons involved in the rehabilitation and integration process of people with disabilities.

Principles of full citizenship of persons with disabilities through inclusive new technologies:

- Availability – Does it exist? Is it obtainable?
- Accessibility – Is it reachable, approachable, convenient?
- Ease of use – Is it functional, practical, understandable, user-friendly and applicable?
- Affordability – Can the expense be met?
- Awareness – Is its existence known to users and stakeholders?
- Appropriateness and attractiveness – Is it suitable, fitting, and appealing?
- Adaptability – Is it adjustable?
- Compatibility – Can it be used together with other relevant products?

In drawing up national strategies governments should, with due respect to national priorities, pay particular attention to the following specific recommendations for priority policy areas. For the purpose of this report the following policy areas are mentioned:

- prevention, identification and diagnosis;
- medical rehabilitation;
- research and development.

Prevention, identification and diagnosis

The use of new technologies should be optimised to help prevent congenital impairment by improved methods and services of screening, scanning and diagnostics, including prenatal genetic testing, and should be carried out in compliance with ethical principles. Action should be taken to maximise the use of existing technologies and to plan the development of new technologies for the diagnosis, assessment and follow-up of sensorial, physical and cognitive impairments.

Medical rehabilitation

Since chronic conditions and degenerative diseases pose major health threats to the individual, competent medical treatment, assistance and care, making use of suitable technology, should be available. Clients, relatives and other carers should be able to make an informed choice of treatment, assistance or care, including the use of specific technologies. New technologies should be used to enhance the effectiveness and efficiency of personal care in accordance with the user's requirements and preferences.

Any medical and functional rehabilitation programme should include full provision of the choice, supply and use of appropriate assistive technology devices including their adjustment, maintenance and replacement. Training in the use of the devices should be available to all persons requiring it. Rehabilitation processes should be adopted in order to attain and/or retain the functional abilities necessary to use the technological products and services available.

Research and development

Since new technologies hold a strong potential to improve the quality of life of persons with disabilities, governments should support research and development programmes aimed at using that potential. The programmes should address technological features in mainstream systems, products and services as well as assistive technology devices.

Research, development and manufacture of new technologies for rehabilitation should be promoted. In order to make optimal use of new technology applications for persons with disabilities, research is needed on methodologies for their introduction, training and use. Research and development in this field should be interdisciplinary and involve human sciences and social sciences in addition to technology and rehabilitation or biomedicine. A broad, holistic perspective should be applied in order to cover the different aspects of the relationship between an individual and technology. Thus, efforts should be co-ordinated between different disciplines, funding sources and other actors.

The involvement and influence of disability organisations is vital in order to set the right priorities for research and development programmes. In order to ensure the practical application of research and development results, close co-operation between researchers, industry and users should be sought. Support for user participation in research and development projects should be provided.

2.15. Recommendation Rec(2001)12 of the Committee of Ministers to member states on the adaptation of health care services to the demand for health care services of people in marginal situations

The preamble of Recommendation Rec(2001)12 considers that problems specific to persons living in marginal situations have serious consequences on their health and that this becomes a public health problem of growing importance and a serious and costly burden for the individual, the family, the community and the state. Due to the growth of inequalities in health in the European countries, any relevant and effective health policy should not only consider the health problems of the persons living in marginal situations but also those of the persons living in insecure conditions, health promotion being one of the key components of such a policy.

The recommendation notes that it is now largely documented that psychological stress experienced by persons living in such insecure conditions has an effect on their physical and mental health. Persons living in insecure situations have the right to live in conditions favourable to their proper development free from physical and psychological overload, social isolation, psychosomatic symptoms related to stress and other forms of handicap. The recommendation makes reference to Article 11 of the European Social Charter on the right to health protection and Article 3 of the Convention on Human Rights and Biomedicine on the equitable access to health care.

There is no specific disease of the poor. Persons living in marginal situations suffer from the same diseases as the rest of the population but in a disproportionate way. The social and health policies need to be grounded on aims to prevent impoverishment and ill-health, where other than merely health and social sectors matter. All policies need to be assessed and evaluated in terms of their impacts on social cohesion, social exclusion and health. This implies intersectoral action and accountability of all policies, including economic and trade policies, in terms of their implications for social well-being, health, equity and marginalisation of people. The health systems have to be based on equity guaranteeing access to care according to need and financing of care regardless of the ability to pay.

Prevention, health promotion and health care measures for persons living in marginal situations or in insecure conditions should be an integral and integrated dimension of national and local social/health policy.

Children are particularly vulnerable in deprived conditions, governments should pay particular attention to them in ensuring that they will benefit from specific social/health preventive policies. All children should be offered a complete programme of immunisation and equal access to paediatric health services and all women should receive antenatal, birth and postnatal care in appropriate health facilities.

Screening and rehabilitation should be offered to anyone regardless of his/her economic, social and cultural status. Physical access to all facilities for the disabled should be secured. Each person should have an equal access to curative services including secondary and tertiary hospital care, where most people in marginal situations usually end up due to emergencies.

Health promotion and preventive services should be organised at local level with particular emphasis on outreach activities toward people living in marginal situations. Persons living in marginal situations or in insecure conditions are often poorly informed. Communication should be improved for informing them about existing programmes and services and how to reach them.

Health services should be offered to everyone but special attention should be paid to persons living in insecure conditions, avoiding stigmatisation:

- Women living in insecure conditions have a higher rate of premature birth and perinatal morbidity, so they should benefit from special social/health surveillance during pregnancy and the perinatal period.
- Children with social/family risk factors should receive special attention from social/health services.
- Families with economic and/or social difficulties should receive support in educating their children, with an emphasis on measures directly benefiting the recipient children (educational vouchers, food stamps, etc.).
- Specific social/health services should be implemented at local level for young people having family/social risks factors with special emphasis on information on family planning, STD, HIV/Aids, traffic accidents, suicide, drug abuse, alcohol, etc. Their general physical and psychosocial well-being should be regularly assessed.
- Social/health services should pay particular attention to the needs of disabled persons whatever the origin of the handicap.
- Special attention should be paid to the needs of persons living in marginal situations with chronic diseases as well as with metabolic or neurological pathologies.
- Occupational health should be developed in particularly exposed working places.

- People living in prison and their children living in collective institutions should benefit from health services of equally good quality as outside prison.
- For underprivileged groups of population including refugees, recent migrants, etc., special attention should be paid to the specific cultural dimension of health. Some key social/health services should include professionals coming from such populations.
- Health care for elderly persons living in insecure conditions should be developed within the community by specially trained social/health workers.
- Specialised services should be available for alcohol and drug abusers.

2.16. Recommendation 1560 (2002) of the Parliamentary Assembly to the Committee of Ministers towards concerted efforts for treating and curing spinal cord injury

The Parliamentary Assembly notes with concern that there are estimated to be at least 330 000 people living with spinal cord injury (paraplegia and tetraplegia) in the member states of the Council of Europe, with about 11 000 new cases every year. Some 40% to 50% of these injuries are the result of road accidents and most occur at a young age. The Assembly emphasises that policies in regard to people with disabilities should be consistent with human rights principles as reflected in the relevant Council of Europe instruments and seek to promote dignity, independence, equality of opportunity, active participation, full citizenship and quality of life. These objectives can be served, among other things, by progress in the search for a cure for spinal cord injury.

The Assembly underlines that advances made in health care and emergency health services have resulted in increasing numbers of people with spinal cord injury surviving and living relatively satisfactorily in the community with their disability, often in a wheelchair and for a near average lifespan. For lack of a cure, that is, neurological restoration leading to functional recovery, priority so far has been given to rehabilitation aimed at increasing functioning and alleviating the symptoms of people with spinal cord injury. Despite high hopes that current research will lead to a cure, the present reality is that interdisciplinary rehabilitation is the only effective treatment that can be provided.

The Assembly believes that, as part of a comprehensive policy for people with disabilities, more intensive efforts must be made to achieve further progress in research designed to bring about a cure for spinal cord injury, and that it is also indispensable to increase the possibilities for rehabilitation with a view to maximising the active life of those with spinal cord injuries. Services aimed at rehabilitation should not be neglected and should be provided effectively and fairly, it being particularly important to provide care and access to treatment for the most disadvantaged, including in developing countries.

Among the recommendations to the Committee of Ministers, the Assembly recommend in particular in relation to preventive measures to urge member states:

- to initiate or step up advertising campaigns designed to reduce road traffic accidents, falls, violence, and the consumption of drugs and alcohol, which are seasonally targeted, where appropriate, to coincide with periods of increased incidence of spinal cord injury, such as summer or winter holidays;
- to establish specialist spinal cord injury departments where necessary within accident and emergency centres, with a view to making them more accessible to those in need of treatment or rehabilitation, even in low population density areas.

Reply from the Committee of Ministers adopted at the 831st meeting of the Ministers' Deputies (12 March 2003)

The Committee of Ministers stresses that the principle of early intervention is very much in keeping with its own philosophy as set out in Recommendation No. R (92) 6 on a coherent policy for people with disabilities. The latter aims, inter alia, at "preventing or eliminating disablement, preventing its deterioration and alleviating its consequences" (Chapter I. 1), and at stimulating and promoting research (Chapter XII. 2). Consequently, the Committee of Ministers considers that early admission for treatment in specialist rehabilitation centres and adequate funding for scientific research is essential.

The Committee of Ministers underlines that the rehabilitation and integration of people with disabilities goes beyond medical issues relating to possible cure and treatment. Recommendation No. R (92) 6 sets out a comprehensive model programme encompassing all stages in the rehabilitation and integration process, and all areas of life and participation in society. It also stipulates that "research should be part of a coherent general policy referring to all aspects of human life and society" (Chapter XII. 2.4).

Attention should be drawn to the impact new technologies can have on the quality of life of persons with disabilities. In this respect, the Committee of Ministers would like to refer to its Resolution ResAP(2001)3 "Towards full citizenship of people with disabilities through inclusive new technologies", and to the report of the Committee on the Rehabilitation and Integration of People with disabilities (Partial Agreement) (CD-P-RR) "The impact of new technologies on the quality of life of persons with disabilities".

Finally, the Committee of Ministers underlines the significance of the European Year of People with Disabilities 2003 and that the Council of Europe's main contribution will be the holding of the Second European Conference of Ministers responsible for integration policies for people with disabilities on 7-8 May 2003 in Malaga, Spain. The theme for the Conference will be "Improving the quality of life of people with disabilities: enhancing a coherent policy for and through full participation". In that context, the Committee of Ministers may look into the possibilities of instructing the appropriate intergovernmental committees to develop strategies to promote spinal cord injury research and prevention as well as access for people with disabilities to new medical technologies.

2.17. Recommendation 1562 (2002) of the Parliamentary Assembly to the Committee of Ministers on controlling the diagnosis and treatment of hyperactive children in Europe

The Parliamentary Assembly is concerned that increasing numbers of children in certain Council of Europe member states are being diagnosed as suffering from “attention deficit/hyperactivity disorder” (ADHD), “hyperkinetic disorder” or related behavioural conditions and treated by means of central nervous system stimulants, such as amphetamines or methylphenidate, which are controlled drugs listed in Schedule II of the 1971 United Nations Convention on Psychotropic Substances because they have been judged by the World Health Organization to be liable to abuse, to constitute a substantial risk to public health, and to have little to moderate therapeutic usefulness.

Although their precise causes are unknown, the validity of ADHD and hyperkinetic disorders, defined in terms of persistent and severe behavioural symptoms centred on inattention, hyperactivity and impulsiveness, and resulting in functional impairment, is widely recognised by professional medical, psychological and scientific organisations, including the World Health Organization. However, the Assembly is concerned that two different sets of criteria are applied in diagnosing these disorders: one adopted by the American Psychiatric Association and used worldwide, the other, more stringent, by the World Health Organization. The Assembly considers that the basis for these different standards should be examined with a view to clarifying and harmonising the criteria governing diagnosis and treatment.

The consensus view is that these behaviourally defined disorders can significantly impair the social, educational and psychological development of some children, resulting in poor self-esteem and emotional and social problems, and severely hampering attainment of their educational potential. The symptoms of ADHD may continue into adolescence and adulthood, and may be accompanied by continuing emotional and social problems, resulting in unemployment, criminality and substance abuse. The toll on those suffering from these disorders, as well as on their families and on society cannot be measured precisely, but may be considerable.

Reply from the Committee of Ministers adopted at the 833rd meeting of the Ministers' Deputies (26 March 2003)

The issues covered by the Recommendation 1562 (2002) were the subject of a meeting which the Pompidou Group held in Strasbourg on 8-9 December 1999 and which was attended by specialists from 15 European countries, the United States and the World Health Organization (WHO). The Committee of Ministers agrees with the Pompidou Group that some of the points raised in the Recommendation are at variance with the views held by the vast majority of the scientific community and that they are dangerously close to certain well-known theories which the "Church of Scientology" has promoted for some time but which do not stand up to serious scientific scrutiny.

The Pompidou Group states that these theories are not only without any scientific basis but, if acted upon, would pose serious health risks to the children in question by depriving them of appropriate treatment. Among these theories, the central one plays down – indeed, disputes – the classification of attention deficit/hyperactivity disorder and hyperkinetic disorder (ADHD/HKD) as illnesses. Yet the overwhelming medical consensus is that, though difficult to diagnose, these disorders not only exist but are a serious lifelong handicap requiring multidisciplinary assessment and treatment by various methods, including drugs.

However, the Committee of Ministers agrees with the Assembly, and with the Pompidou Group, that in the light of the serious individual problems connected with ADHD/HKD and the adverse effects which these disorders have on family and social life, it is necessary to step up research into the causes and possible remedies so as to further improve diagnostic methods and criteria and identify appropriate treatments.

The Committee of Ministers also agrees with the Assembly, and with the Pompidou Group, that control must be exercised over diagnosis and treatment of ADHD/HKD. It appears that the situation differs in this respect from country to country and that, in some countries, treatment of ADHD/HKD by methylphenidate is not allowed. In other countries a need for greater supervision cannot be ruled out.

2.18. Recommendation 1592 (2003) of the Parliamentary Assembly to the Committee of Ministers towards full social inclusion of people with disabilities

According to the Parliamentary Assembly, some of the fundamental rights contained in the European Convention on Human Rights, its Protocols, and the Revised European Social Charter are still inaccessible to many people with disabilities: the right to education; the right to work; the right to private and family life; the right to protection of health and social security; the right to protection against poverty and social exclusion; the right to adequate housing, etc.

The right to receive support and assistance, although essential to improving the quality of life of people with disabilities, is not enough. Guaranteeing access to equal political, social, economic and cultural rights should be a common political objective for the next decade. Equal status, inclusion, full citizenship, and the right to choose should be further promoted and implemented. The granting of rights, although necessary, is not sufficient.

The Parliamentary Assembly notes with satisfaction that in certain member states policies concerning people with disabilities have been gradually evolving over the past decade from an institutional approach, considering people with disabilities as “patients”, to a more holistic approach, viewing them as "citizens" who have a right to individual support and self-determination.

The year 2003, declared European Year of People with Disabilities by the Council of the European Union, will be an opportunity to induce a real change in attitudes towards people with disabilities and their rights by raising the awareness of decision makers, professionals and the general public by means of a more active involvement of European organisations, national governments, social partners, the mass media, and various non-governmental and advocacy groups across Europe. The Assembly recommends that, in the course of the European Year of People with Disabilities 2003, the Committee of Ministers invites all member states to report regularly on progress made in the implementation of its Recommendation No. R (92) 6 on a coherent policy for people with disabilities.

The Assembly recommends that, in the course of the European Year of People with Disabilities 2003, the Committee of Ministers instruct the relevant bodies of the Council of Europe:

- to give consideration to including explicit reference to discrimination on the grounds of disability in the two main Council of Europe legal instruments: the European Convention on Human Rights (Article 14); and the Revised European Social Charter (Part V, Article E);
- to adopt an action programme for the full social inclusion of people with disabilities in Europe, as a follow-up to the Second European Conference of Ministers responsible for Integration Policies for People with Disabilities.

2.19. Malaga Ministerial Declaration on people with disabilities adopted at the Second European Conference of Ministers responsible for integration policies for people with disabilities, 7-8 May 2003

At the invitation of the Spanish Government, the Second European Conference of Ministers responsible for integration policies for people with disabilities was held in Malaga, Spain, on 7 and 8 May 2003.

The general theme of the conference was "Improving the quality of life of people with disabilities: enhancing a coherent policy for and through full participation". Sub-themes were "Promoting citizenship and full participation by developing effective legal and policy provisions to ensure equality of opportunities for people with disabilities", and "Developing innovative approaches on services, intended to meet the needs of people with disabilities as consumers". Proposals to enhance the integration of women with disabilities and that of people with disabilities in need of a high level of support were discussed as cross-cut issues.

The main objective of the Conference was to develop common principles which should permeate future disability policy development and public service delivery. To that end, Ministers discussed the achievements and shortcomings of recent and current integration policies for people with disabilities and ways of meeting the new challenges. They exchanged ideas, shared experiences, and discussed measures taken, or to be taken, at national, European, and international level to improve the quality of life of people with disabilities.

The outcome of that debate, the "Malaga Ministerial Declaration on People with disabilities: "Progressing towards full participation as citizens" initiates the elaboration of an ambitious, detailed but flexible European Action Plan to implement at national and international level the principles evoked at this Second European Conference.

The Ministers responsible for integration policies for people with disabilities recommend:

- that the Committee of Ministers of the Council of Europe continues to promote policies aimed at ensuring full citizenship and active participation of people with disabilities, with the full participation of all member states, and to strengthen the role of the Council of Europe as a platform for international co-operation in the field of disability policy-making by inviting the Committee on the Rehabilitation and Integration of People with disabilities and other relevant Council of Europe committees to further mainstream disability policies within their areas of competence;

- the elaboration, taking into account the considerations raised at this Ministerial Conference, of a Council of Europe Action Plan for people with disabilities: a new European policy framework for the next decade, based on human rights and partnership between different actors, setting up strategic objectives and priority issues in order to achieve full citizenship and active participation of people with disabilities in the life of the community, through workable, affordable and sustainable policies;
- that the Council of Europe plays an active role in the negotiations in the context of the forthcoming sessions of the United Nations Ad Hoc Committee established "to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities", by making use of the Council's extensive experience in human rights matters.

Concerning the prevention of disability, the Malaga Ministerial Declaration contains the following statement:

> We, the Ministers responsible for integration policies for people with disabilities, gathered on 7 and 8 May 2003 in Malaga on invitation of the Spanish government, at the Second European Conference of Ministers, organised by the Council of Europe, consider that it is a basic objective to develop economic, social, educative, employment, environmental and health measures in order to maintain every disabled individual's maximum capacity over the life course and in order **to help prevent disability.**
>
> *Malaga Ministerial Declaration on People with disabilities: "Progressing towards full participation as citizens", paragraph 21.*

2.20. Committee of Experts on the prevention of disabilities linked to chronic diseases (P-RR-PREV)

The Committee on the Rehabilitation and Integration of People with disabilities (Partial Agreement) (CD-P-RR) adopted at its 23rd session the specific terms of reference for the Committee of Experts on the prevention of disabilities linked to chronic diseases (Partial Agreement) (P-RR-PREV).

Specific terms of reference:

Within the general framework of the terms of reference of the CD-P-RR and in compliance with the provisions which, in Recommendation No. R (92) 6 on a coherent policy for people with disabilities, aim at enhancing, on the one hand, the identification of impairments and early diagnosis (Section III of the Appendix); and on the other, prevention and health education (Section II of the Appendix):

a. to make proposals to governments aimed at reducing disabilities caused by chronic diseases and, to this end:

b. to exchange information on policies to prevent disabilities caused by chronic diseases;

c. to draw up an in-house document setting out what are agreed to be the most appropriate means of prevention;

d. to prepare a draft resolution for the CD-P-RR to submit to the Committee of Ministers;

e. to publish a Council of Europe white paper on the prevention of disabilities caused by DCDs in Europe. This document will provide the “historical background” to the work of the committee of experts.

In the course of the work of the Committee, points c. to e. of the specific terms of reference were revised as to mean the drafting of a report and recommendations on the prevention of disabilities linked to chronic diseases.

Contribution to the Second European Conference of Ministers

For the Second European Conference of Ministers responsible for integration policies for people with disabilities the Committee of Experts prepared a contribution called “prevention of disabilities linked to chronic diseases.”

Extracts from the contribution:

A disease-specific approach alone seems no longer appropriate, since a common denominator resulting from these demographic and epidemiological changes is functional dependency creating a growing need for care to manage everyday life and for measures to prevent social exclusion.

Adequate care for people with chronic diseases is only possible if, apart from the medical treatment, the family, social and professional environment of the person concerned is integrated into the care measures, and if the person with a chronic disease is regarded as the active manager of his/her disease.

Just like any other persons, people with chronic diseases and disabilities have a right to life, to respect of their human dignity, to physical integrity, and to free personal development. This means that persons with chronic diseases and disabilities have a right to equality of opportunity, independent living, active participation in the life of community, and a good quality of life. In short, they have the right to full citizenship. The forthcoming report lists measures that facilitate the enjoyment of these rights by people with disabilities linked to chronic diseases which are potentially disabling.

Primary and secondary prevention measures for chronic diseases aim at preventing their occurrence and at limiting, by early screening and care, their impact on people’s health. Such measures must be developed but they alone are not sufficient to avoid the occurrence of disabilities and participation restrictions of people suffering from them. That is why we suggest to deal more particularly with all the measures to limit such disabilities, to compensate for them, and to guarantee full participation of people with chronic diseases of whatever kind. Consequently, the forthcoming report will contain recommendations on general measures common to all disabilities caused by chronic diseases as well as specific provisions relating to disabilities caused by particular chronic diseases.

The Council of Europe Recommendation No. R (92) 6 on a coherent policy for people with disabilities stipulates that preventive action should be taken as early as possible to prevent an impairment from arising or worsening, to reduce as far as possible the degree of disability for a given impairment, and to reduce any social disadvantage arising from a given disability.

In addition to the measures to detect, treat and diagnose impairments at an early stage, steps should be taken to ensure individualised and community programmes of rehabilitation, including follow-up and evaluation, as well as the necessary support to individuals and their families. These programmes should take account, inter alia, of each individual's specific situation and problems, with the help of functional diagnosis, in order to prevent any secondary (emotional, cognitive, mental, motor or social) effects of the impairment with the help of early educational measures targeted at the individual and the creation of awareness in the family and the sector of society concerned.

The forthcoming report does not attempt to provide an exhaustive list of all possibilities of preventive action. This would be impossible, given the large number of chronic diseases and the very different types of disabilities among individuals.

The report does intend, however:

- to use examples of chronic diseases in order to describe measures which, in the context of virtually all chronic diseases, can contribute to preventing, delaying or alleviating impairments and disabilities, and also to avoid participation restrictions which could follow, and

- to demonstrate that despite the fact that the possibilities of prevention have improved substantially during the past years, additional measures have to be considered for all persons with chronic diseases and the results have to be put into practice in everyday life.

Chronic diseases with both high and low incidence were taken into account. It will also be demonstrated that preventive action is necessary regardless of the age of the person concerned and that physical as well as mental illnesses also have to be considered.

General measures for the prevention of disabilities linked to chronic diseases:

I. Measures of health care promotion (quality of care)

1. Development of neighbourhood facilities for the co-ordination of care at all levels, notably by using interdisciplinary teams in the field of health care at community level. This development should be based on multidisciplinary education and training of health care professionals, taking account of social and environmental dimensions of chronic diseases and of those measures that have a social impact (quality of life).
2. Reinforcement and extension of professional home care, including help in professional and social integration, in order to enable the person with a disability to choose his/her care setting, and to prevent and/or delay institutional care as much and as long as possible, if he/she so wishes.
3. Promotion of the actual (voluntary) help of families, close relations, family associations or other appropriate NGOs, reinforcement of family associations, self-help groups and mutual aid associations, training of families and close relations, and promotion of their know-how and expertise.
4. Realisation of so-called "(interdisciplinary) expert centres" ensuring equity of access for both top-level long-term care and rehabilitation as well as for short stays during aggra-

vation of the disease, for the benefit of patients of all ages, including people with rare chronic diseases.

5. Guarantee of a 100% financial coverage of the costs of medical assistance and care directly linked to long-term illnesses.

II. Measures of social impact (quality of life)

1. *a*. Structural improvement of financial support for people with disabilities and their families taking care of them, for example through measures of extra social insurance or substantial tax-deduction.

   b. Access to the built environment and necessary and appropriate human help and assistive technology.

   c. Directly connected with this issue is the creation of the possibility of special respite or holidays without negative financial consequences for the people involved.
2. Removal of restrictions on the access to loans and insurance policies.
3. Guarantee that employment regulations are non-discriminatory in terms of access to work and at the same time provide protection in case of disease-related complications, such as in cases of the inevitable absenteeism caused by the disease.
4. Enhancement of employment opportunities for people with disabilities with the necessary support.
5. Promotion of day centres and of networking of such centres, if appropriate.
6. Access to culture, leisure and appropriate sports-activities.
7. Promotion of the use of universal design/ “Design for All”-concept. (c.f. Council of Europe Resolution ResAP (2001) 1 on the introduction of the principles of universal design into the curricula of all occupations working on the built environment).

8. Guarantee of a sufficient supply of appropriate (adapted or adaptable) houses for people with disabilities.
9. Promotion of the inclusion of children with disabilities in mainstream education taking into account the specific needs of children with chronic diseases, in particular with regard to their health care needs.

III. Measures of general prevention by informing the public (quality of information and knowledge)

1. Promotion of public awareness not only on the existence, but also on the impact and the long-term effect and social consequences of chronic diseases, notably the risk of social exclusion, by giving regularly and thoroughly relevant information.
2. Promotion of the public awareness on the subject of health and health-care by the general "level-wide" introduction of specific education on the issues of health and nutrition, in curricula and educational programmes at school level, notably on the risk of social exclusion.

Specific measures for the prevention of disabilities linked to chronic diseases

The Committee of Experts has also identified specific difficulties linked to certain chronic diseases. Examples included the isolation and the loss of normal day and night-time rhythms which were frequent complications with dementia, and the inability of schizophrenic or frontal syndrome patients to recognise their condition or relate normally to others. Constraints inherent in the treatment of other chronic diseases (e.g. oxygen treatment for advanced COPD, nausea or pain as side effects of certain cancer treatments) could interfere with patients' activity. Discrimination at work could also result, for example, from absenteeism. However, the solutions to these various problems must be adapted to the context. The Committee is currently studying ways and means of designing appropriate and effective measures to prevent disability.

2.21. Oslo declaration following the 7th Conference of European Health Ministers "Health, Dignity and Human Rights", 12-13 June 2003

The Council of Europe, with its human rights vocation, has the obligation to defend human rights and dignity. This protection can only be achieved through strong social cohesion, equal rights to health care and an ethical and human rights framework, within which health care is delivered.

The European Health Ministers, gathered in Oslo, on 12 and 13 June 2003:

- recognise that providing appropriate and good quality care is a responsibility of every government in general and particularly Health Ministers; this goes beyond the mere delivery of health services and encompasses the respect of the dignity of the individual, which acquires particular importance in our modern multicultural societies;
- agree that health care services should function within a human rights framework as promoted by the Council of Europe, keeping in mind that vulnerability is not necessarily the lot of certain social groups and restricted to certain age groups, but can hit anybody at any time;
- agree to give high priority to identifying the needs of all those individuals and groups who are socially excluded and mobilise the necessary human and financial resources for an appropriate response to their health needs;
- are fully aware of the increasing importance for health issues and health implications to become an integral part of policies and decisions in all sectors of government, due to the constant need to respond to new health problems resulting from social and environmental policies; Ministries responsible for health must play a leading role in providing evidence on health consequences of policies in other areas;
- are fully aware that solidarity can no longer be limited to one's own population; it has to be extended to other countries facing similar challenges;

- agree to increase efficiency and safety in health care through alliances, bilateral or multilateral with other countries, including the public and private sectors, in order to facilitate sharing experiences, knowledge and technology and for carrying out research jointly;
- commit ourselves to work together to bridge the knowledge gap and to provide a more equal distribution of health technologies, taking into account that the member states undergo to a large extent, but at a different pace, the same changes in society, and should respond politically according to national priorities and possibilities;
- agree to monitor the advances in information technology and in relevant research for the purpose of appropriate handling of patients' information, with full respect of safety, privacy and confidentiality and to assess their contribution to patients' empowerment;
- agree to work towards a proper balance between preventive and curative care, with a marked insistence on the development of healthy lifestyles, to stimulate responsibility of individuals towards their own health, and ensure citizen participation in the decision making process concerning health care.

Chapter 3 – World Health Organization

3.1. Health for All

In 1946, the Constitution of the World Health Organization (WHO) was adopted by the member states. The constitution proclaimed that “the enjoyment of the highest attainable standard of health” was “one of the fundamental human rights of every human being without distinction for race, religion, political belief, economic or social condition”. The Constitution also noted that “the health of all peoples is fundamental in the attainment of peace and security and is dependent upon the fullest co-operation of individuals and states”.

Health for All was adopted in 1977 and launched at the UNICEF/WHO International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978 to underline the fact that despite the ambitious proclamations enshrined in the WHO Constitution, large numbers of people and even whole countries, were not enjoying an acceptable standard of health. By the late 1970s nearly 1 billion people were living in poverty. The International Conference on Primary Health Care in Alma-Ata expressed the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world.

The Conference strongly reaffirmed that health, which is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, is a **fundamental human right** and that the attainment of the highest possible level of health is a most important world-wide social goal whose realisation requires the action of many other social and economic sectors in addition to the health sector.

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care. Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organisations and the whole world community should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice.

Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.

Primary health care reflects and evolves from the economic conditions and socio-cultural and political characteristics of the country and its communities and is based on the application of the relevant results of social, biomedical and health services research and public health experience, addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly, includes at least:

- education concerning prevailing health problems and the methods of preventing and controlling them;
- promotion of food supply and proper nutrition;
- an adequate supply of safe water and basic sanitation;

- maternal and child health care, including family planning;
- immunisation against the major infectious diseases;
- prevention and control of locally endemic diseases;
- appropriate treatment of common diseases and injuries; and
- provision of essential drugs.

The International Conference on Primary Health Care called for urgent and effective national and international action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical co-operation and in keeping with a New International Economic Order. It urges governments, WHO and UNICEF, and other international organisations, as well as multilateral and bilateral agencies, non-governmental organisations, funding agencies, all health workers and the whole world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries.

3.2. WHO International Conferences on Health Promotion

3.2.1. First International Conference on Health Promotion, Ottawa, Canada, 17-21 November 1986

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being.

The fundamental conditions and resources for health are peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity. Improvement in health requires a secure foundation in these basic prerequisites. Good health is a major resource for social, economic and personal development and an important dimension of quality of life. Political, economic, social, cultural, environmental, behavioural and biological factors can all favour health or be harmful to it. Health promotion action aims at making these conditions favourable through advocacy for health.

Health promotion focuses on achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men.

The prerequisites and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands co-ordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organisations, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities. Professional and social groups and health personnel have a major responsibility to mediate between differing interests in society for the pursuit of health.

Health promotion goes beyond health care. It puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health. Health promotion policy combines diverse but complementary approaches including legislation, fiscal measures, taxation and organisational change. It is co-ordinated action that leads to health, income and social policies that foster greater equity. Joint action contributes to ensuring safer and healthier goods and services, healthier public services, and cleaner, more enjoyable environments.

Health promotion policy requires the identification of obstacles to the adoption of healthy public policies in non-health sectors, and ways of removing them. The aim must be to make the healthier choice the easier choice for policy-makers as well.

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitute the basis for a socio-ecological approach to health. The overall guiding principle for the world, nations, regions and communities alike is the need to encourage reciprocal maintenance – to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasised as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organises work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable. Systematic assessment of the health impact of a rapidly changing environment – particularly in areas of technology, work, energy production and urbanisation – is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies. Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.

Health promotion supports personal and social development through providing information, education for health and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health. Enabling people to learn throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has to be facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and within the institutions themselves.

The responsibility for health promotion in health services is shared among individuals, community groups, health professionals, health service institutions and governments. They must work together towards a health care system which contributes to the pursuit of health.

The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services. Health services need to embrace an expanded mandate which is sensitive and respects cultural needs. This mandate should support the needs of individuals and communities for a healthier life, and open channels between the health sector and broader social, political, economic and physical environmental components.

Reorienting health services also requires stronger attention to health research as well as changes in professional education and training. This must lead to a change of attitude and organisation of health services, which refocuses on the total needs of the individual as a whole person.

Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members. Caring, holism and ecology are essential issues in developing strategies for health promotion. Therefore, those involved should take as a guiding principle that, in each phase of planning, implementation and evaluation of health promotion activities, women and men should become equal partners.

3.2.2. Second International Conference on Health Promotion, Adelaide, Australia, 5-9 April 1988

The Adelaide Conference on Healthy Public Policy continued in the direction set at Alma-Ata and Ottawa, and built on their momentum. The Conference identified four key areas as priorities for health public policy for immediate action:

Supporting the health of women

This Conference proposes that countries start developing a national women's healthy public policy in which women's own health agendas are central and which includes proposals for:

- equal sharing of caring work performed in society;
- birthing practices based on women's preferences and needs;
- supportive mechanisms for caring work, such as support for mothers with children, parental leave, and dependent health care leave.

Food and nutrition

The Conference recommends that governments take immediate and direct action at all levels to use their purchasing power in the food market to ensure that the food-supply under their specific control (such as catering in hospitals, schools, day-care centres, welfare services and workplaces) gives consumers ready access to nutritious food.

Tobacco and alcohol

This Conference calls on all governments to consider the price they are paying in lost human potential by abetting the loss of life and illness that tobacco smoking and alcohol abuse cause. Governments should commit themselves to the development of healthy public policy by setting nationally-determined targets to reduce tobacco growing and alcohol production, marketing and consumption significantly by the year 2000.

Creating supportive environments

Many people live and work in conditions that are hazardous to their health and are exposed to potentially hazardous products. Such problems often transcend national frontiers. Environmental management must protect human health from the direct and indirect adverse effects of biological, chemical, and physical factors, and should recognise that women and men are part of a complex ecosystem. The extremely diverse but limited natural resources that enrich life are essential to the human race.

This Conference advocates that, as a priority, the public health and ecological movements join together to develop strategies in pursuit of socio-economic development and the conservation of our planet's limited resources.

3.2.3. Third International Conference on Health Promotion, Sundsvall, Sweden, 9-15 June 1991

Third International Conference on Health Promotion: Supportive Environments for Health calls upon people in all parts of the world to actively engage in making environments more supportive to health. Examining today's health and environmental issues together, the Conference points out that millions of people are living in extreme poverty and deprivation in an increasingly degraded environment that threatens their health, making the goal of Health for All by the Year 2000 extremely hard to achieve. The way forward lies in making the environment – the physical environment, the social and economic environment, and the political environment – supportive to health rather than damaging to it. The Sundsvall Conference identified many examples and approaches for creating supportive environments that can be used by policy makers, decision makers and community activists in the health and environment sectors. The Conference recognised that everyone has a role in creating supportive environments for health.

3.2.4. Fourth International Conference on Health Promotion, Jakarta, Indonesia, 21-25 July 1997

The Jakarta Declaration on Health Promotion offers a vision and focus for health promotion into the next century. It reflects the firm commitment of participants in the Fourth International Conference on Health Promotion to draw upon the widest possible range of resources to tackle health determinants in the 21st century.

Demographic trends such as urbanisation, an increase in the number of older people and the high prevalence of chronic diseases pose new problems in all countries. Other social, behavioural and biological changes such as increased sedentary behaviour, resistance to antibiotics and other commonly available drugs, increased drug abuse, and civil and domestic violence threaten the health and well-being of hundreds of millions of people.

New and re-emerging infectious diseases, and the greater recognition of mental health problems, require an urgent response. It is vital that approaches to health promotion evolve to meet changes in the determinants of health. Research and case studies from around the world provide convincing evidence that health promotion is effective. Health promotion strategies can develop and change lifestyles, and have an impact on the social, economic and environmental conditions that determine health. Health promotion is a practical approach to achieving greater equity in health. The five strategies set out in the Ottawa Charter for Health Promotion are essential for success:

- build healthy public policy;
- create supportive environments;
- strengthen community action;
- develop personal skills;
- reorient health services.

There is now clear evidence that:

- Comprehensive approaches to health development are the most effective. Those that use combinations of the five strategies are more effective than single-track approaches.
- Particular settings offer practical opportunities for the implementation of comprehensive strategies. These include mega-cities, islands, cities, municipalities, local communities, markets, schools, the workplace, and health care facilities.
- Participation is essential to sustain efforts. People have to be at the centre of health promotion action and decision-making processes for them to be effective.
- Health learning fosters participation. Access to education and information is essential to achieving effective participation and the empowerment of people and communities.

3.2.5. Fifth Global Conference on Health Promotion, Mexico, Mexico, 5-9 June 2000

The Conference sought to demonstrate how health promotion strategies add value to the effectiveness of health and development policies, programmes and projects, particularly those that aim to improve the health and quality of life of people living in adverse circumstances. Its specific objectives were to:

- Show how health promotion makes a difference to health and quality of life, especially for people living in adverse circumstances.
- Place health high on the development agenda of international, national and local agencies.
- Stimulate partnerships for health between different sectors and at all levels of society.

3.2.6. International Classification of Functioning, Disability and Health (ICF) and WHO Conference on Health and Disability, Trieste, Italy, 17-20 April 2002

Seventy countries gathered from 17 to 20 April 2002 in Trieste during the World Health Organization Conference on Health and Disability to outline how they can use a groundbreaking new tool to classify functioning, health and disability so that disability is seen as part of a wider concept of health. By focusing on how people function and what they need to live to their full potential, the classification can help end isolation and stamp out discrimination.

The Conference was a major ministerial meeting, following up the launch of the International Classification of Functioning, Disability and Health (ICF) in November 2001. The Italian Government has taken a leading position in promoting the possibilities ICF provides as a tool for new understanding and policy development.

The ICF has been accepted by 191 countries as the international standard to describe and measure health and disability. Using the ICF framework, WHO estimates that as much as 500 million healthy life years are lost each year due to disability associated with health conditions. This is more than half the years that are lost annually due to premature death. The ICF provides a common metre about this immense problem.

While traditional health indicators are based on the mortality (i.e. death) rates of populations, the ICF shifts focus to “life”, i.e., how people live with their health conditions and how these can be improved to achieve a productive, fulfilling life. It has implications for medical practice, for law and social policy to improve access and treatment; and for the protection of the rights of individuals and groups. ICF changes the understanding of disability which is presented not as a problem of a minority group, nor just of people with a visible impairment or in a wheelchair. For example, a person living with HIV/AIDS could be disabled in terms of his/her ability to participate actively in a profession. In that case, the ICF provides different perspectives as to how measures can be targeted to optimise that person's ability to remain in the workforce and live a full life in the community.

The ICF takes into account the social aspects of disability and provides a mechanism to document the impact of the social and physical environment on a person's functioning. For instance, when a person with a serious disability finds it difficult to work in a particular building because it does not provide ramps or elevators, the ICF identifies the needed focus of an intervention, i.e. that the building should include those facilities and not that the person be forced out of the job because of an inability to work. ICF puts all disease and health conditions on an equal footing irrespective of their cause. A person may not be able to attend work because of a cold or angina, but also because of depression. This neutral approach puts mental disorders on a par with physical illness and has contributed to the recognition and documentation of the worldwide burden of depressive disorders, which is currently the leading cause, worldwide, of life years lost due to disability.

3.3. World Health Organization Regional Office for Europe programmes

3.3.1. Vaccine-preventable Diseases and Immunisation

The WHO Regional Office for Europe programme on Vaccine-preventable Diseases and Immunisation aims to co-ordinate and guide the European member states in enhanced control of diseases, in partnership with them and with international and bilateral agencies. Major initiatives include the strengthening of immunisation delivery systems, the introduction of new antigens, elimination of measles in the Region linked with accelerated prevention of congenital rubella syndrome, and participation in the global poliomyelitis eradication effort.

With the successes of vaccination and decreases in the burden of these diseases, questions about the safety of some of these vaccines are frequently raised. None the less, extensive experience and research have demonstrated that the vaccines in use today are highly effective and safe. Reaching and maintaining high coverage of children at the appropriate age with the recommended doses of vaccine, including children of vulnerable groups, are the goals and challenges faced.

The use of modern vaccines is recognised as one of the most cost-effective health interventions available. Starting with the introduction of vaccination against smallpox (variola) using the milder infection, cowpox (vaccinia), a global programme ultimately led to eradication of the disease, certified in 1980. Early successes with vaccines led to the development of many others. The Expanded Programme on Immunisation (EPI) was established in 1977 to protect children's health through routine immunisation against complications of tuberculosis, diphtheria, tetanus, pertussis, poliomyelitis and measles. Globally, this effort is now called the Expanding Programme on Immunisation, to include new antigens, such as vaccination against hepatitis B. European scientists have been at the forefront of vaccine research, and European public health programmes have included effective immunisation programmes for decades. Nevertheless, many challenges are being faced, particularly in the transition economies with health care reform in the newly independent states and countries of central and eastern Europe.

3.3.2. The European Network of Health Promoting Schools (ENHPS)

The Council of Europe, the European Commission and the World Health Organization Regional Office for Europe joined forces in 1991/1992 to create the European Network of Health Promoting Schools (ENHPS). Beginning as a pilot project in four of the countries of central and eastern Europe, the Network now includes over 500 pilot schools with 400,000 students, in 38 countries. More than 5,000 schools are linked to the Network through national or regional arrangements. The Network does not belong to the three sponsoring international organisations, but is supported by them. It belongs to the actors in the project. The project's primary objective is to improve and protect the welfare of pupils, teachers, non-teaching staff and the wider community.

Over the past years the Network has expanded rapidly because the health and education sectors see the Network as a consolidating initiative, gathering together knowledge and understanding about health promotion in the school setting within a network of pilot schools. With partnership as both method and goal, the Network provides a flexible framework in which schools can determine their needs and work to meet them in their own ways. Health promoting schools commit themselves to promoting health in schools by making them safe and health-enhancing social and physical environments.

3.3.3. Promotion of young people's health

The European programme for the promotion of young people's health works through the European Network of Health Promoting Schools. Because the determinants of education and health are indivisibly linked, work to help young people must address both. The health promoting school is based on a social model of health. This emphasises the entire organisation of the school, as well as focusing upon the individual. At the heart of the model is the young person, who is viewed as a whole individual within a dynamic environment.

Such an approach creates a highly supportive social setting that influences the visions, perceptions and actions of all who live, work, play and learn in the school. This generates a positive climate that influences how young people form relationships, make decisions and develop their values and attitudes. Healthy, well-educated young people can help to reduce inequities in society, thus contributing to the health and wealth of the population at large.

3.3.4. Children's health and environment (CHE)

The children's health and environment (CHE) programme advocates the rights of children to live and grow in an environment that allows them to reach their highest attainable level of health. The programme pursues this goal by:

- co-ordinating activities in the European Region;
- taking part in the global community; and

- working for the implementation of the recommendations from the Third Ministerial Conference on Health and Environment (1999) and contributing to the next Conference (Budapest, 2004).

Increasing hazards where children live are raising concern about the effects of the deterioration of the environment on their health. Children have a special vulnerability to environmental pollution, and their specific exposure patterns make them subject to higher exposures.

Although children's health in the WHO European Region is currently satisfactory on the whole, warning signals are emerging. They include the return of diseases previously under control (for example, diphtheria and tuberculosis), the increase of chronic diseases (for example, asthma and allergies), and the new morbidity from substance abuse, injuries and mental disorders. Adverse effects on children's health also result from increasing socio-economic inequalities across the Region, the consequences of armed conflict, child labour and the sexual exploitation of minors.

3.3.5. Mental health

WHO/Europe's programme on mental health designs and implements mental health activities for the European Region as a whole. Several expert committees, with consumers' participation, support the Regional Office's efforts in mental health:

- The WHO Task Force on Depression and Stress-Related Morbidity collects information to promote research and establish guidelines for action.
- The WHO Task Force on Mental Health Assessments monitors national programmes on mental health.
- The WHO Task Force on De-stigmatisation analyses stigma on and social exclusion of people with mental health problems, and elaborates and disseminates evidence-based strategies to member states.

- The WHO European Network on Suicide Prevention gathers data, exchanges experience and develops comprehensive strategies for suicide prevention.

In the past year, the programme has worked to increase the importance of mental health in national health and social agendas, using World Health Day 2001 and activities related to it as a framework. The programme primarily works through a network of national counterparts in 46 countries, supported by more than 30 WHO collaborating centres.

3.3.6. Countrywide integrated non-communicable diseases intervention (CINDI)

The countrywide integrated non-communicable diseases intervention (CINDI) programme works to improve health and the quality of life in communities by reducing premature death, disease and disability from major non-communicable diseases, including cardiovascular diseases, cancer, chronic respiratory diseases, accidents, diabetes and mental disorders. Its objectives are to enable member states:

- to develop measures for integrated disease prevention and health promotion as part of their primary health care systems in order to reduce morbidity by reducing common risk factors; and
- to establish effective collaborative mechanisms and methodologies to implement these measures.

CINDI provides participating countries with an integrated approach to activities to prevent and control risk factors (such as smoking, high blood pressure, high blood cholesterol, obesity and excessive alcohol consumption) and to address their social and environmental determinants. CINDI puts existing knowledge in participating countries to use – first in demonstration projects in small areas and then countrywide. In addition, its member countries form a network in which they can share their experience in developing their national programmes.

3.3.7. Healthy ageing

The concept of active ageing was launched at the Second World Assembly on Ageing in Madrid 8-12 April 2002. Active Ageing is the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age. WHO/Europe is highlighting the issues associated with active ageing, i.e. fostering policy advocacy, promoting healthy lifestyles, reducing health risks and increasing quality of life, because ageing will put increased economic and social demands on all countries of the WHO European Region. At the same time, older people provide a precious, often ignored resource that makes an important contribution to the socio-economic fabric of our lives. One useful way to look at decision-making in this area is to think about enablement – restoring function and expanding the participation of older people in all aspects of society – instead of disablement – increasing the needs of older people, leading to isolation and dependence.

A variety of sectors can enact “age-friendly” policies that prevent disability and enable those who have disabilities to fully participate in community life.

- City authorities can offer well-lit streets for safe walking and appropriate transport systems.
- Recreation services can offer exercise programmes that help older people maintain or recover their mobility.
- The education sector can offer life-long learning and literacy programmes.
- Social services can provide hearing aids or instruction in sign language to enable continued communication.
- The health sector can offer enabling rehabilitation programmes as well as cost-effective procedures such as cataract surgery and vaccinations against influenza.

Governments and international agencies can offer credit schemes and businesses can modify the work environment so that older people can continue to earn an income and to participate in development activities.

3.3.8. Healthy workplaces

The programme for healthy workplaces:

- supports selected countries in carrying out community-based, cross-sectoral projects for health at work;
- strengthens preventive services that support different aspects of health and work;
- promotes networking by key stakeholders in workplace health; and
- assesses the workplace's impact on general health (contribution to health impact assessment).

Comprehensive workplace health promotion empowers social partners inside and outside enterprises to maintain their own health and that of their families as well as to create an environment supportive of health. Knowledge of occupational, lifestyle, environmental and social determinants of health are needed.

This may require reorienting existing workplace health services. Interventions aimed at the workplace must be community based, owing to the growing number of small-scale enterprises and the need to cover sufficient population for meaningful epidemiological analysis. Health benefits are gained through the integration of health, environment and safety issues in the overall management of enterprises. Health outcomes can be evaluated at the community level, using both the rate of work-related injuries and diseases and the WHO public health indicators relevant for populations of working age.

3.3.9. Accidents, transport and health

European countries face the conflicting needs of transport policies. While transport has a key role in the economy, concern is increasing about the harm to health and the environment of current transport policies and about their social sustainability. Promoting healthy and sustainable transport alternatives prevents the negative effects of transport patterns on human health. To do this, intersectoral co-operation and high-level political commitment must ensure that health issues are considered when transport policies are formulated.

As mandated by the Third Ministerial Conference on Environment and Health (1999), the transport programme facilitates a shift in the current strategies towards full consideration of transport policies' implications for development, the environment and health, focusing on:

- developing methods and tools for health impact assessment (HIA) to support member states in the definition and management of mobility policies beneficial to health;
- developing policies for transport sustainable for health and the environment; and
- promoting healthy transport modes.

The programme co-operates with many organisations, including the United Nations Economic Commission for Europe (UN ECE), the Organisation for Economic Co-operation and Development (OECD), the European Environment Agency (EEA), the United Nations Environmental Programme (UNEP) and the European Commission, as well as with non-governmental organisations and with the WHO Healthy Cities project.

3.3.10. Health effects and risks of transport systems (HEARTS)

HEARTS promotes healthier transport policies through the development of tools that support the integration of health impact assessments in the decision-making process. The project focuses on health risks associated with air pollution and noise and with injuries, especially within vulnerable groups such as children and elderly people. HEARTS tools are based on models of exposures and health effects generated by different transport policies. Scenarios will be developed and linked to provide integrated estimates of health effects. These models will be embedded into a geographical information system (GIS) and tested by three European pilot cities. HEARTS models specifically address traffic and emissions, air pollution, noise, traffic accidents, time activity and exposures, and health effects.

Transport patterns, along with smoking and diet, are among the most important health determinants in Europe. Air pollution, noise and traffic accidents all contribute to a wide range of harmful effects, including respiratory and cardio-vascular disease, physical injury and stress-related illnesses. Unhealthy transport patterns also encourage a sedentary lifestyle by reducing opportunities for physical activity such as walking and cycling.

Chapter 4 – International Labour Organization (ILO), United Nations and European Union

4.1. ILO Safe Work: Global Programme on Safety, Health and the Environment

One of the key functions of the International Labour Organization from its inception has been the establishment of international standards on labour and social matters. These international labour standards take the form of Conventions and Recommendations. About 70 of them deal with occupational safety and health matters. In addition to the ILO Conventions and Recommendations dealing with occupational safety and health matters, further guidance is provided in Codes of Practice and manuals which are used as reference material by those in charge of formulating detailed regulations or responsible for occupational safety and health. In some cases other instruments like resolutions have been introduced to address a certain problem.

Around the world, millions of men and women work in poor and hazardous conditions: According to the ILO, every year, more than 2 million people die of work-related accidents and diseases. More than 160 million workers fall ill each year due to workplace hazards.

The Global Programme on Safety, Health and the Environment has four major goals:

1. preventive policies and programmes are developed to protect workers in hazardous occupations and sectors;
2. effective protection is extended to vulnerable groups of workers falling outside the scope of traditional protective measures;

3. governments and employers' and workers' organisations are better equipped to address problems of workers' well-being, occupational health care and the quality of working life;
4. the social and economic impact of improving workers' protection is documented and recognised by policy and decision makers.

Showing that protection pays. The prevention of accidents, improvement of working conditions and enforcement of standards are often seen as a cost to business. Little is known about the costs of not preventing accidents or poor working conditions, or of the benefits of improvements for productivity and competitiveness. Better information and analytical tools can help increase firms' and governments' willingness to invest in prevention. This strategy will have two main thrusts: extending the knowledge base through a major drive for comprehensive, reliable and sustainable data, and new research on the economics of labour protection. The programme will foster the development of a safety culture worldwide.

Protecting workers in hazardous conditions. Priority must be given to workers in the most hazardous occupations and sectors, such as mining, construction or agriculture, or where working relationships or conditions create particular risks, such as very long working hours, exposure to hazardous chemicals, work in isolation and work by migrants, etc. The ILO will make use of its extensive experience in the development of standards, codes of practice and technical guides in exploiting the world's information resources, and in developing means of practical action. Member states will be encouraged to set objectives and targets for the protection of workers in hazardous conditions. Particular attention will be given to strengthening the advisory and enforcement capacity of labour inspectorates.

Extending protection. The large majority of workers whose conditions are most in need of improvement are excluded from the scope of existing legislation and other protective measures. Existing policies and programmes need to be reviewed to extend their coverage. This will go hand in hand with action to strengthen labour inspectorates' capacity to develop broad prevention policies and programmes and to promote the protection of vulnerable workers, particularly women workers. Alliances and networks will be extended to include ministries of health, industry, local government, education, and social services, as well as local community groups. Emphasis will also be placed on achieving tangible results through practical action and exchanges of information on good practices.

Promoting workers' health and well-being. The strategy to promote workers' health and well-being will involve the establishment of a data bank on policies, programmes and good enterprise-level practices so as to improve the capacity to identify workers' protection issues and to provide guidance on new approaches. Governments' capacity for prevention, protection, and the application and enforcement of key labour protection instruments will be strengthened.

The major outputs will be the following:

Protecting workers in hazardous jobs:

- a World Report on Life and Death at Work, presenting the world situation regarding risks, accidents and diseases, policies and experience, and guidance for future action;
- a film on safety and health, focusing on manifestly hazardous conditions;
- new standards on safety and health in agriculture established through tripartite agreement;
- a review of standards on occupational safety and health to determine the action needed to update and possibly consolidate them, and to translate them into practical policy and programmatic tools such as codes of practice and guidelines;
- tools and guidance for member states to facilitate the ratification and implementation of ILO standards;

- harmonised chemical labelling systems, safety data sheets and hazard communication methods;
- guidelines for radiation protection and the classification of radiographs of pneumoconiosis;
- a rapid response capacity, especially on chemical safety and health issues, including readily accessible networks and timely information.

Extending protection to all workers:

- training programmes and tools for owners of SMEs (small- and medium-sized enterprises) to promote labour protection and improve productivity;
- strengthening the effectiveness, efficiency and coverage of labour inspection systems;
- guidelines for the extension of labour protection to informal sector workers;
- partnerships with community organisations and others to develop and implement approaches for reaching out to hard-to-reach groups of workers.

Promoting workers' health and well-being:

- a data bank on policies, programmes and good enterprise-level practices;
- training methodologies and diagnostic tools;
- guidelines on occupational health care for all;
- programmes to prevent and deal with the effects of workplace problems, including drugs, alcohol and stress.

Showing that protection pays:

- a statistical programme to develop new survey tools, carry out national surveys;
- better national and global estimates of occupational fatalities and injuries;
- report on the economics of accidents and preventive measures;

- tools for inspection services to promote the benefits of prevention;
- guides on occupational safety and health management systems and safety culture;
- tools to reduce work-related environmental damage.

Promoting national and industry-based action:

- a global technical co-operation programme on safety, health and the environment;
- national and industry-level programmes of action to tackle priority issues.

Strategies

The ILO's traditional strategy – and that of most ILO member states – has involved:

1) ILO standards (Conventions, codes) ratified, adapted into national laws, directives, rules and codes of practice and application mechanisms for these.
2) Enforcement and advisory services by labour inspection including specialised services (mining, construction and other technical and targeted inspections).
3) Knowledge: information services and research.
4) Advocacy: training, promotion, partnerships.
5) Alliances, technical co-operation and twinning, and resource mobilisation.

A new complementary strategy can be based on the principles of occupational safety and health management systems:

A. At the enterprise level the ILO-OSH 2001 "Guidelines on Occupational Safety and Health Management Systems" can be adapted to the company's needs.

B. At the sectoral, regional, national and international levels the set up of action programmes based on the ILO-OSH 2001 principles (P-D-C-A, plan-do-check-act) and tripartite collaboration.

C. A National Safe Work Programme should consist of:

- a national policy;
- a structure and organisation – including structures of employers and workers and other partners – and to implement such a policy, this must include setting of clear responsibilities, accountabilities and allocation of resources;
- an implementation plan that has objectives, time limits and targets that can be measured by agreed indicators;
- implementation including the traditional measures listed above
- feed-back, review, auditing and adjustment of the policies, structures and implementation.

4.2. UN World Programme of Action concerning Disabled Persons

The World Programme of Action concerning Disabled Persons was adopted by the United Nations General Assembly at its 37th regular session on 3 December 1982, by its Resolution 37/52. The purpose of the World Programme of Action concerning Disabled Persons is to promote effective measures for prevention of disability, rehabilitation and the realisation of the goals of "full participation" of disabled persons in social life and development, and of "equality". This means opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development. These concepts should apply with the same scope and with the same urgency to all countries, regardless of their level of development.

Prevention of impairment, disability and handicap

The technology to prevent and control most disablement is available and improving but is not always fully utilised. Member states should take appropriate measures for the prevention of impairment and disability and ensure the dissemination of relevant knowledge and technology.

Co-ordinated programmes of prevention at all levels of society are needed. They should include:

- community-based primary health care systems that reach all segments of the population, particularly in rural areas and urban slums;
- effective maternal and child health care and counselling, as well as counselling for family planning and family life;
- education in nutrition and assistance in obtaining a proper diet, especially for mothers and children, including the production and utilisation of foods rich in vitamins and other nutrients;
- immunisation against communicable diseases, in line with the objectives of the Expanded Programme of Immunisation of the World Health Organization;
- a system for early detection and early intervention;
- safety regulations and training programmes for the prevention of accidents in the home, in the workplace, on the road and in leisure-related activities;
- adaptation of jobs, equipment and the working environment and the provision of occupational health programmes to prevent the generation of occupational disabilities or diseases and their exacerbation;
- measures to control the imprudent use of medication, drugs, alcohol, tobacco and other stimulants or depressants in order to prevent drug-related disability, particularly among schoolchildren and elderly people. Of particular concern also is the effect upon unborn children of imprudent consumption of these substances by pregnant women;
- educational and public health activities that will assist people in attaining life-styles that will provide the maximum defence against the causes of impairment;
- sustained education of the public and of professionals as well as public information campaigns related to disability prevention programmes;

- adequate training for medical, paramedical and other persons who may be called upon to deal with casualties in emergencies;
- preventive measures incorporated in the training of rural extension workers to assist in reducing incidence of disabilities;
- well-organised vocational training and practical on-the-job training of workers with a view to preventing accidents at work and disabilities of different degrees. Attention should be paid to the fact that outdated technology is often used in developing countries. In many cases, old technology is transferred from industrial countries to developing countries. The old technology, inappropriate for the conditions in developing countries, together with insufficient training and deficient labour protection, contributes to an increased number of accidents at work and to disabilities.

Rehabilitation

Rehabilitation services are often provided by specialised institutions. However, there exists a growing trend towards placing greater emphasis on the integration of services in general public facilities. There has been an evolution in both the content and the spirit of the activities described as rehabilitation. Traditional practice viewed rehabilitation as a pattern of therapies and services provided to disabled persons in an institutional setting. Often under medical authority. This is gradually being replaced by programmes which, while still providing qualified medical, social and pedagogical services, also involve communities and families and help them to support the efforts of their disabled members to overcome the disabling effects of impairment within a normal social environment. Increasingly it is being recognised that even severely disabled persons can, to a great extent, live independently if the necessary support services are provided.

Many disabled persons require technical aids. In some countries the technology needed to produce such items is well developed, and highly sophisticated devices are manufactured to assist the mobility, communication and daily living of disabled individuals. The costs of such items are high, however, and only a few countries are able to provide such equipment. Many people need simple equipment to facilitate mobility, communication and daily living. Such aids are produced and available in some countries. In many other countries, however, they cannot be obtained because of a lack of their availability and/or of high cost. Increasing attention is being given to the design of simpler, less expensive devices, with local methods of production which are more easily adapted to the country concerned, more appropriate to the needs of most disabled persons and more readily available to them.

4.3. UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities

In the 1990s, as a significant outcome of the United Nations Decade of Disabled People (1983-1992) the Standard Rules on the Equalisation of Opportunities for People with Disabilities were adopted by the forty-eighth session of the General Assembly in 1993. The Standard Rules are an international instrument with a human rights perspective for disability-sensitive policy design and evaluation.

Although the Rules are not compulsory, they can become international customary rules when they are applied by a great number of states with the intention of respecting a rule in international law. They imply a strong moral and political commitment on behalf of states to take action for the equalisation of opportunities for people with disabilities. Important principles for responsibility, action and co-operation are indicated. Areas of decisive importance for the quality of life and for the achievement of full participation and equality are pointed out. The Rules offer an instrument for policy-making and action to people with disabilities and their organisations. They provide a basis for technical and economic co-operation among states, the United Nations and other international organisations.

The Standard Rules on the Equalisation of Opportunities for People with Disabilities consists of 22 rules summarising the message of the World Programme of Action. The Rules incorporate the human rights perspective which had developed during the Decade. The 22 rules concerning disabled persons consist of four chapters – preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism – and cover all aspects of life of disabled persons.

Preconditions for equal participation are:

- Awareness-raising (Rule 1)
- Medical care (Rule 2)
- Rehabilitation (Rule 3)
- Support services (Rule 4)

Rule 1. Awareness-raising

According to Rule 1, states should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution. Responsible authorities should distribute up-to-date information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public.

Information to persons with disabilities should be presented in accessible form. States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.

Rule 1 says that the portrayal of persons with disabilities by the mass media should be encouraged in a positive way; organisations of persons with disabilities should be consulted on this matter.

Furthermore, states should ensure that public education programmes reflect in all their aspects the principle of full participation and equality. States should invite persons with disabilities and their families and organisations to participate in public education programmes concerning disability matters. States should encourage enterprises in the private sector to include disability issues in all aspects of their activity. States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them. Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities of their own organisations. Awareness-raising also should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.

Rule 2. Medical care

According to Rule 2, states should ensure the provision of effective medical care to persons with disabilities. States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organisations of persons with disabilities at the planning and evaluation level. Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.

States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society. States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology. States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.

Finally, states should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

Rule 3. Rehabilitation[1]

According to Rule 3, states should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality. Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.

All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it. Persons with disabilities and their families should be able to participate in the design and

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[1] The term "rehabilitation" refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.

organisation of rehabilitation services concerning themselves. Rule 3 stipulates that all rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organised, where appropriate, in residential form.

Furthermore, persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors. States should draw upon the expertise of organisations of persons with disabilities when formulating or evaluating rehabilitation programmes.

Rule 4. Support services

According to Rule 4, states should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights. States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalisation of opportunities.

States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them. To achieve this, generally available technical know-how should be utilised. In States where high-technology industry is available, it should be fully utilised to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible. Persons with disabilities themselves could be involved in the production of those devices.

Rule 4 stipulates that states should recognise that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them. In rehabilitation programmes for the provision of assistive devices and equipment, states should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness of assistive devices and equipment.

Finally, states should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities. Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

4.4. Public health policy of the European Union

The Treaty on European Union (Maastricht, 1992) stipulates in Article 6 that the European Union is founded on the principles of liberty, democracy, respect for human rights and fundamental freedoms, and the rule of law and that the European Union will respect fundamental rights, as guaranteed by the Convention for the Protection of Human Rights and Fundamental Freedoms and as they result from the constitutional traditions common to the member states, as general principles of Community law.

The Treaty of Amsterdam (1997) introduced a new Article 152 (former Article 129) in the Treaty establishing the European Community (Rome, 1957) stipulating:

Title XIII (former Title X)

Public Health

Article 152 (former Article 129)

1. A high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities.

Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education.

The Community shall complement the member states' action in reducing drugs-related health damage, including information and prevention.

2. The Community shall encourage co-operation between the member states in the areas referred to in this Article and, if necessary, lend support to their action.

Member states shall, in liaison with the Commission, coordinate among themselves their policies and programmes in the areas referred to in paragraph 1. The Commission may, in close contact with the member states, take any useful initiative to promote such co-ordination.

3. The Community and the member states shall foster cooperation with third countries and the competent international organisations in the sphere of public health.

4. The Council, acting in accordance with the procedure referred to in Article 251 and after consulting the Economic and Social Committee and the Committee of the Regions, shall contribute to the achievement of the objectives referred to in this Article through adopting:

(a) measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives; these measures shall not prevent any Member State from maintaining or introducing more stringent protective measures;

(b) by way of derogation from Article 37, measures in the veterinary and phytosanitary fields which have as their direct objective the protection of public health;

(c) incentive measures designed to protect and improve human health, excluding any harmonisation of the laws and regulations of the member states.

The Council, acting by a qualified majority on a proposal from the Commission, may also adopt recommendations for the purposes set out in this Article.

5. Community action in the field of public health shall fully respect the responsibilities of the member states for the organisation and delivery of health services and medical care. In particular, measures referred to in paragraph 4(a) shall not affect national provisions on the donation or medical use of organs and blood.

According to the Commission of the European Communities, people in the European Union are now living longer and leading healthier lifestyles than ever before. A range of indicators ranging from life expectancy, infant mortality and maternal mortality confirm this trend. However, one in five citizens still dies prematurely, often due to preventable diseases. New risks to health, especially communicable diseases, are emerging, there are disturbing inequalities in health status between social classes and longer life expectancy is itself creating its own problems such as a sharp rise in age-related diseases such as Alzheimer’s.

A comprehensive Community strategy on public health has been in place since November 1993, following the ratification of the Maastricht Treaty which gave the Community an explicit competence in this field. Essentially, the European Union is now able to play a role in prevention measures. To implement this new provision, the European Union action is organised under several programmes, dealing with specific diseases or public health concern:

- Health promotion,
- Cancer,
- Drug abuse,
- Health monitoring,
- Injury prevention,
- Tobacco,
- AIDS and other communicable diseases,
- Pollution-related diseases,
- Rare diseases.

Decision No. 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 adopting a programme of Community action in the field of public health (2003-2008)

The Community is committed to promoting and improving health, preventing disease, and countering potential threats to health, with a view to reducing avoidable morbidity and premature mortality and activity-impairing disability. To contribute to the well-being of European citizens, the Community must address in a co-ordinated and coherent way the concerns of its people about risks to health and their expectations for a high level of health protection. Therefore, all health related activities of the Community must have a high degree of visibility and transparency and allow consultation and participation of all stakeholders in a balanced way, in order to promote better knowledge and communication flows and thus enable a greater involvement of individuals in decisions that concern their health. In this framework, attention should be given to the right of the Community population to receive simple, clear and scientifically sound information about measures to protect health and prevent diseases, with a view to improving quality of life.

Health is a priority and a high level of health protection should be ensured in the definition and implementation of all Community policies and activities. Under Article 152 of the

Treaty, the Community is required to play an active role in this sector by taking measures which cannot be taken by individual States, in accordance with the principle of subsidiarity. In the context of the public health framework set out in the Commission communication of 24 November 1993 on the framework for action in the field of public health, eight action programmes were adopted, namely:

- Decision No. 645/96/EC of the European Parliament and of the Council of 29 March 1996 adopting a programme of Community action on health promotion, information, education and training within the framework for action in the field of public health (1996 to 2000),
- Decision No. 646/96/EC of the European Parliament and of the Council of 29 March 1996 adopting an action plan to combat cancer within the framework for action in the field of public health (1996 to 2000),
- Decision No. 647/96/EC of the European Parliament and of the Council of 29 March 1996 adopting a programme of Community action on the prevention of AIDS and certain other communicable diseases within the framework for action in the field of public health (1996 to 2000),
- Decision No. 102/97/EC of the European Parliament and of the Council of 16 December 1996 adopting a programme of Community action on the prevention of drug dependence within the framework for action in the field of public health (1996 to 2000),
- Decision No. 1400/97/EC of the European Parliament and of the Council of 30 June 1997 adopting a programme of Community action on health monitoring within the framework for action in the field of public health (1997 to 2001),
- Decision No. 372/1999/EC of the European Parliament and of the Council of 8 February 1999 adopting a programme of Community action on injury prevention in the framework for action in the field of public health (1999 to 2003),
- Decision No. 1295/1999/EC of the European Parliament and of the Council of 29 April 1999 adopting a programme of

Community action on rare diseases within the framework for action in the field of public health (1999 to 2003), and

- Decision No. 1296/1999/EC of the European Parliament and of the Council of 29 April 1999 adopting a programme of Community action on pollution-related diseases in the context of the framework for action in the field of public health (1999 to 2001).

Furthermore, Decision No. 2119/98/EC of the European Parliament and of the Council of 24 September 1998 on setting up a network for the epidemiological surveillance and control of communicable diseases in the Community was adopted. Pursuant to that Decision, the Commission adopted on 22 December 1999 Decision No. 2000/57/EC on the early warning and response system for the prevention and control of communicable diseases.

The Council on 18 November 1999 agreed unanimously a Resolution on the Promotion of Mental Health. According to the

WHO World Health Report 2000 the five major burdens of disease (in disability-adjusted life years) are:

1. neuropsychiatric disorders,
2. cardiovascular diseases,
3. malignant neoplasms,
4. unintentional injuries,
5. respiratory diseases.

Infectious diseases, such as HIV/AIDS, and anti-microbial resistance are also becoming a threat to the health of all people in Europe. An important task of the programme would be to identify better the main burdens of disease in the Community and, in particular, the main health determinants.

The overall aim of the public health programme is to contribute towards the attainment of a high level of physical and mental health and well-being and greater equality in health matters throughout the Community, by directing action towards improving public health, preventing human diseases and disorders, and obviating sources of danger to health with a view to combating morbidity and premature mortality, while taking gender and age into consideration. To fulfil this aim, actions should be guided by the need to increase life expectancy without disability or sickness, promote quality of life and minimise the economic and social consequences of ill health, thus reducing health inequalities, while taking into account the regional approach to health issues. Priority should be given to health-promoting actions that address the major burdens of disease. The programme should support the development of an integrated intersectoral health strategy to ensure that Community policies and actions contribute to protecting and promoting health.

The programme shall be implemented in the period starting on 1 January 2003 and ending on 31 December 2008. The general objectives of the programme shall be:

a. to improve information and knowledge for the development of public health;

b. to enhance the capability of responding rapidly and in a co-ordinated fashion to threats to health;

c. to promote health and prevent disease through addressing health determinants across all policies and activities.

The activities of the programme are the following:

a. activities related to the monitoring and rapid reaction systems;

b. activities on health determinants;

c. activities related to legislation;

d. activities related to consultation, knowledge and information;

e. promotion of co-ordination at the European level of non-governmental organisations which are developing activities defined as priorities under the programme. They may be operating either singly or in the form of several co-ordinated associations.

In the course of implementing the programme, co-operation with third countries and with international organisations competent in the sphere of public health, in particular the World Health Organization, the Council of Europe and the Organisation for Economic Co-operation and Development, or able to have an impact on public health such as the World Trade Organization and the United Nations Food and Agriculture Organization shall be encouraged.

4.5. European Community strategy on health and safety at work 2002-2006

Safety and health at work now constitutes one of the European Union’s most concentrated and most important social policy sectors. As early as 1951, the European Coal and Steel Community set about improving the safety of workers, a concern which the Treaty of Rome extended to all employed people. As a result, a substantial corpus of legislation aimed at raising standards of safety and health has developed since the late 1970s, and especially since the Single European Act was adopted in 1987.

It is because the European Union can call on such an abundant source of material that it is crucial for the social policy agenda to set out a Community strategy. This strategy, which covers the period 2002-2006, has three novel features:

- It adopts a global approach to well-being at work, taking account of changes in the world of work and the emergence of new risks, especially of a psycho-social nature. As such, it is geared to enhancing the quality of work, and regards a safety and healthy working environment as one of the essential components.
- It is based on consolidating a culture of risk prevention, on combining a variety of political instruments – legislation, the social dialogue, progressive measures and best practices, corporate social responsibility and economic incentives – and on building partnerships between all the players on the safety and health scene.
- It points up the fact that an ambitious social policy is a factor in the competitiveness equation and that, on the

other side of the coin, having a "non-policy" engenders costs which weigh heavily on economies and societies.

Strengthening the prevention culture

The Community's policy on health and safety is based on preventive approaches bringing in all the players, including the workers themselves, with a view to developing a genuine culture of risk prevention, the aim being to anticipate risks and bring them under control.

Education, awareness, anticipation: improving people's knowledge of risks

Creating a controlled work environment means improving everyone's knowledge of the risks. This means developing an approach which is both global and preventive, geared to promoting well-being at work, and going beyond the mere prevention of specific risks. There are three mutually supportive elements.

1. Education does not start with entry into the world of work, as the Economic and Social Committee has pointed out: it should be part and parcel of the school curriculum, either with a view to making people more aware of the problem (much like road safety is taught in some countries), or as a vocational subject in its own right. However, the most important element here is continuing vocational training. This must be dispensed regularly and be geared to the realities of day-to-day work, with a view to impacting directly on the work environment. It means that the teaching has to be targeted to national, regional, local and sectoral specificities and sensitivities.
2. Awareness training must mobilise resources which are varied and geared to specific situations, e.g. SMEs (small- and medium-sized enterprises), very small firms and craft trade workers. These people and organisations must be made aware of the need to reintegrate disabled people into employment, with special reference to creating an adapted work environment. The need to adapt the workplace to the needs of disabled people is covered by

Directive 89/654, and the concept of "reasonable adaptations" is defined in Directive 2000/78 (OJ L 303/16, 2 December 2000).

3. Anticipating new and emerging risks, whether they be linked to technical innovation or caused by social change, is vital if the risks are to be brought under control. This requires, first and foremost, ongoing observation of the risks themselves, based on the systematic collection of information and scientific opinions. The European Parliament has stressed that this kind of analysis is an integral part of a preventive approach. It also requires researchers to adopt a consistent approach: research organisations should co-ordinate their respective programmes, target them to address practical problems arising at the workplace, and make preparations for the research findings to be transferred to firms, and especially to SMEs. The European Agency for Safety and Health at Work should act as a driving force in matters concerning awareness-building and risk anticipation. In the second half of 2002, the Commission will present a communication assessing the work of the Agency, and spelling out the role the Agency should be playing in this field.

The European Agency for Health and Safety at Work:

- will set up a "risk observatory", based on examples of good practice collected from firms or specific branches of activity;
- will organise exchanges of experience and information by way of the systematic collection of data, with the support of Eurostat;
- will integrate the candidate countries into these information networks, and devise working tools which are geared to their specific situation;
- will refocus the European week on health and safety on users and final beneficiaries;
- will establish, for the European Year of People with Disabilities (2003), a data base of best practices and information concerning ways of integrating disabled people

and adapting equipment and the work environment to their needs.

Better application of existing law

Applying Community law effectively is essential in order to improve the quality of the work environment. This in turn requires an enhanced state of awareness on the part of all concerned, and at all levels. The Commission will, in conjunction with the Advisory Committee and the social partners, be producing guides on how to apply the directives, taking account of the diverse nature of sectors of activity and companies, as suggested by the Economic and Social Committee.

For its part, the Commission will, subject to the powers bestowed on it by the Treaty, adopt a rigorous approach to ensuring that directives are properly transposed and the law is properly applied. It will also be co-operating closely with the national authorities to find ways of ensuring that Community directives are implemented correctly and equivalently. In this respect, a fundamental role will fall to the Senior Labour Inspectors Committee (SLIC) in terms of encouraging exchanges of information and experience and organising mutual co-operation and assistance. There must be practical encouragement for common inspection objectives as part of an annual action plan, the importance of which has been underlined by the European Parliament, common principles for labour inspection in the field of health and safety at work, and ways and means of evaluating national inspection systems by reference to these principles. Integrating the candidate countries' inspectorates into this committee is a matter of prime importance in terms of promoting the effective implementation of Community law.

While it is important to pay heed to the diversity of the member states' institutional structures and administrative traditions, it is also true that implementing the new strategy, geared to the quality of work and well-being at work, will require thought to be given to which structures are best adapted to this global approach:

- the *prevention services* should be genuinely multidisciplinary, embracing social and psychological risks, and the gender factor;
- *labour inspection* activities must be capable of appraising all the risks, particularly in those sectors where they tend to be complex and cumulative (for example, in hospitals). The inspectorate services must combine their inspection role with a prevention function vis-à-vis firms and workers. They must in turn be open to audit, using result and quality indicators to promote innovative approaches.

The checks carried out by the inspection services must give rise to uniform sanctions which are dissuasive, proportionate and effectively applied. In this regard, two areas take on a special significance:

- Protection of young people, who tend to be more liable to the risk of accidents than other population groups. This will involve, on the one hand, enforcement measures to combat the illegal employment of young people who have not yet reached the legal age and, on the other, for those who are admitted to employment, the rigorous application of the rules on health and safety.
- Some companies operating within the European Union sometimes escape administrative and criminal sanctions if the member state in which they operate is different from that in which they are established. This is the case where they provide limited-duration services outside the country in which their headquarters are based. Article 3 (1) (e) of Directive 96/71/EC of 16 December 1996 concerning the posting of workers in the framework of the provision of services says that firms which send their employees to provide a service in a different European Union member state must, during the period of secondment, apply the same standards of safety, health and hygiene at work as apply in the host country. Co-operation in terms of the mutual exchange of information between public authorities, as provided for in Article 4 of the Directive, is being gradually put into place, and should make it easier to pros-

ecute errant firms. Nonetheless, it is worth looking into all possible ways and means of dealing with infringements in transnational situations, and of strengthening ongoing work on the subject within the SLIC.

4.6. The European Union Disability Strategy

A society open and accessible to all is the goal of the European Union Disability Strategy. The barriers need to be identified and removed. This approach has been stimulated by the United Nations Standard Rules on Equalisation of Opportunities for Persons with Disabilities.

Co-operation between the Commission and the member states

Most of the practical work of making a society accessible can best be achieved in the member states. The subsidiarity principle applies – what can be achieved better at national level shall be done at national level. But even where the member states are the principal actors the Commission may play a part by aiming to:

- strengthen co-operation with and between the member states in the disability field;
- promote the collection, exchange and development of comparable information and statistics and good practice;
- raise awareness of disability issues;
- take account of disability issues in all policy making and legislative work of the Commission – external and internal.

A forum for exchange with the member states is the High Level Group of member states' Representatives on Disability which meets on a regular basis. Awareness-raising is part of the 'European Day of Disabled People' with takes place in December each year and of the National Information Days on disability issues. The year 2003 is planned to be the European Year of Disabled People. Changing attitudes towards people with disabilities in the area of employment is a key issue. Disability aspects are included in the National Action Plans on

Employment and in the National Action Plans against Poverty and Social Exclusion. Some words of interest are statistics, indicators, and accessibility.

In deciding on an Anti-discrimination directive in November 2000 the member states undertook (if they have not already done so) to prohibit discrimination of people with disabilities and others on the labour market and in the workplace and in vocational training. Reasonable accommodation – fitting – of the workplaces to the needs of people who have disabilities is one of major changes in this legislation.

The European Council in Nice (7-9 December 2000) welcomed the joint proclamation, by the Council, the European Parliament and the Commission, of the Charter of Fundamental Rights, combining in a single text the civil, political, economic, social and societal rights hitherto laid down in a variety of international, European or national sources. The European Council would like to see the Charter disseminated as widely as possible amongst the Union's citizens. The question of the Charter's force will be considered later.

Mainstreaming disability in policy formulation

When the Commission creates or changes a policy it aims to consider the needs and rights of people with disabilities. The Commission pays particular attention to disability aspects in its socio-economic policies, programmes and projects.

The Unit for the Integration of People with Disabilities is responsible for mainstreaming disability matters within the Commission. It organises regular meetings with representatives from other Directorates-General in the context of an Interservice Disability Group. Its purpose is to raise awareness of disability matters and to facilitate and encourage co-operation on disability matters among Directorates-General.

Full participation of people with disabilities

The Commission considers that people with disabilities should be involved in the planning, monitoring and evaluation of changes in policies, practises, programmes, etc. The

Commission both encourages others to do so and seeks to do so itself. The Commission's dialogue with the European Disability Forum (EDF) is an example of such practice. (The EDF is an umbrella organisation representing for example European Co-ordinating Disability NGOs and National Disability Councils.)

The Commission is committed to involving the Social Partners in efforts to integrate people with disabilities into the labour market. The Social Partners adopted a Joint Declaration on the Employment of people with disabilities at a meeting of the Social Dialogue Committee on 19 May 1999. Another example is the EQUAL initiative (2000-2006) where social partners and other key players including representatives of groups who are discriminated in relation to the labour market are involved in developing and testing out new ideas on job creation.

The High Level Group on Disability

As proposed by the Commission in its Communication (COM(96) 406 final), the High Level Group is set up to monitor the latest policies and priorities of governments concerning people with disabilities, to pool information and experience, and to advise the Commission on methods for reporting in future on the EU-wide situation with regard to disability. The High Level Group in particular focuses its attention on the orientations set out in Section II of the Resolution adopted by the Council and representatives of governments on 20 December 1996:

- empowering people with disabilities for participation in society, including the severely disabled, while paying due attention to the needs and interests of their families and carers;
- mainstreaming the disability perspective into all relevant sectors of policy formulation and implementation;
- enabling people with disabilities to participate fully in society by removing barriers;

- nurturing public opinion to be receptive to the abilities of people with disabilities and towards strategies based on equal opportunities.

The High Level Group also shares experience with regard to the involvement of representatives of people with disabilities in the implementation and the follow-up of relevant policies and actions in their favour. Furthermore, the High Level Group advises the Commission on the implementation of section II of the Resolution. In these ways, whilst recognising that responsibility in this field lies with the member states, the Commission and member states strengthen co-operation in the field of disability, and encourage the exchange and the development of good practice in the European Union, as agreed in the Resolution.

The Council Resolution and the above mentioned mandate will provide the basis of the work of the High Level Group. The orientations adopted by the Council and the Government representatives reflect the current policy trends which are mainly based on the idea that the environment should be altered to enable people with disability to live independently in the society. This basic principle becomes apparent in terms such as "empowerment", "enablement", "mainstreaming" or "awareness". This approach is in line with a civil rights perspective which focuses on equal opportunities for people with disabilities. However, it is important to acknowledge that despite significant differences in the details of member states programme policies, all disability systems are faced with a set of key policy issues in implementing these guidelines which no one system has satisfactorily resolved. Yet, in every case, each system is trying different policy and programme approaches to resolve these issues. Disability policy is therefore in a dynamic stage of development at EU level. The High Level Group seek therefore to identify and to compare the various approaches to the practical implementation of the Resolution orientations. This will provide a synthesis of member states disability policies which will demonstrate both the complexity and variability of national disability programmes and confirm the major underlying issues which have emerged as essential on a cross national basis.

European Year of People with Disabilities (2003)

The year 2003 was proclaimed European Year of People with Disabilities by the Council of the European Union on 3 December 2001. The objectives of the European Year of People with Disabilities are:

a. to raise awareness of the rights of people with disabilities to protection against discrimination and to full and equal enjoyment of their rights;

b. to encourage reflection on and discussion of the measures needed to promote equal opportunities for people with disabilities in Europe;

c. to promote the exchange of experience of good practice and effective strategies devised at local, national and European level;

d. to reinforce the co-operation between all parties concerned, namely government, the social partners, NGOs, the social services, the private sector, communities, voluntary sector groups, people with disabilities and their families;

e. to improve communication regarding disability and promote a positive image of people with disabilities;

f. to raise awareness of the heterogeneity of people with disabilities and of the various kinds of disability;

g. to raise awareness of the multiple discrimination facing people with disabilities;

h. to pay special attention to awareness of the right of children and young people with disabilities to equality in education, so as to encourage and support their full integration in society and to promote the development of European co-operation between those professionally involved in the education of children and young people with disabilities, in order to improve the integration of pupils and students with special needs in ordinary or specialised establishments and in national and European exchange programmes.

PART II –

REPORT OF THE COMMITTEE OF EXPERTS ON THE PREVENTION OF DISABILITIES LINKED TO CHRONIC DISEASES

1. Introduction

The attention to be given to people with chronic diseases presents the main challenge for the health care and social support systems in the member states of the Council of Europe. For the purpose of this report, the term "chronic disease" is understood to mean any long-term state originating from a pathological process which remains active, with health and/or functional consequences, entailing changes to all or some aspects of the personal, social and/or professional life.

The significance and the impact of chronic diseases on health care and social services will increase in the future for various reasons:

- Even though medical progress is made step by step, there will not be any significant reduction in the prevalence of chronic diseases in the near future.
- Given the performance of health care and social service systems, the life expectancy of people with chronic diseases will increase if these people are appropriately cared for.
- Given the fact that medical progress and appropriate care are increasing longevity, they at the same time increase the risk of contracting chronic diseases of all kinds. Chronic diseases affect in particular older people, whose proportion in the population is increasing significantly in all member states. It should be noted that many elderly people have several chronic diseases at the same time (multi-morbidity).

However, not only older people are affected by chronic diseases, in fact, people of all ages are affected, for example, already about 10% of children and young persons suffer from chronic diseases. The rapid rise on non-communicable diseases represents one of the major challenges to the health and social systems in the future. According to the World Health Organization it is estimated that by 2020 over 70% of the global burden of disease will be caused by non-communicable diseases (especially cancer, diabetes, cardiovascular diseases and chronic respiratory diseases), mental health disorders and injuries.[1] At least half of all medical health care expenditures alone are spent on care for people with chronic diseases. And still, the medical health expenditures of chronic diseases are lower than the social expenses, such as wage replacement payments and loss of production.

Worldwide, the global disease burden has changed rapidly towards chronic conditions, while current health systems are still more often than not designed to provide acute care rather than continuity of care. The near future will see even more dramatic changes in the health needs of the world population, with chronic diseases as the leading cause of disability. These changes require a very different approach to health policy and health or social services. A disease-specific approach is not sufficient, since a common denominator is functional dependency creating a growing need for care and services to optimise everyday life and for measures to prevent social exclusion.

An adequate response to the needs of people with chronic diseases is possible only if, provision of medical treatment, the day-to-day home, family, social, and occupational environment of the person concerned is adapted and that person is considered as the active manager of his/her own life.

While people with disabilities tend to experience more stable conditions, people with chronic diseases may experience specific conditions linked to the developmental nature of the disease.

Just like any other persons, people with chronic diseases have a right to life, to respect of their human dignity, to phys-

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1. www.who.int/noncommunicable_diseases

ical integrity, to free personal development, to equality of opportunity, independent living, active participation in the life of community. They have the right to full citizenship. However, many people with chronic diseases encounter numerous obstacles in effectively accessing these rights in their daily life. In order to remedy this all efforts should be made to prevent disabilities that may be caused by chronic diseases.

This report lists these measures that facilitate the enjoyment of these rights by people with potentially disabling chronic diseases. Partly, these measures fall within already existing general disability policy provisions. These provisions should also be made available to people with chronic diseases (see for instance Council of Europe Recommendation No. R. (92) 6 on a coherent policy for people with disabilities).

The concept and definition of the term “disability” have been – and still are – evolving over time. This committee took the Council of Europe’s Recommendation No. R (92) 6 on a coherent policy for people with disabilities as a reference framework. That recommendation uses the definitions of the terms “impairment”, “disability” and “handicap” as established by the World Health Organization in the International Classification of Impairments, Disabilities and Handicaps (ICIDH) of 1980. Consequently, references to this threefold layer of definitions are also found in this report. However, in the course of the work of this committee, the World Health Organization adopted the International Classification of Functioning, Disability and Health (ICF) in 2001, introducing terms such as “body functions”, “activity limitations” and “participation restrictions”. It is worth noting that the underlying positive concepts are “activity” and “participation”.[1]

The Council of Europe Recommendation No. R (92) 6 on a coherent policy for people with disabilities stipulates that preventive action should be taken as early as possible to prevent

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[1] A more detailed discussion of the definitions of the term “disability” is included in Appendix 1 to this report.

an impairment from arising or worsening, to reduce as far as possible the degree of disability for a given impairment, and to reduce any social disadvantage arising from a given disability.

While primary and secondary prevention measures aim at preventing the occurrence of diseases and impairments and at limiting, by early screening and care, the impact on people's health, in particular on that of children, these measures are not part of the scope of this committee. Furthermore, medical therapy by itself will not be dealt with by this working group either. Such measures must be developed but they alone are not sufficient to avoid the occurrence of disabilities and participation restrictions of people suffering from them. That is why the committee suggest here to deal more particularly with all the measures to compensate the social disadvantages arising from disabilities linked to chronic diseases and to guarantee full participation of people with chronic diseases of whatever kind.[1]

The following text contains specific provisions relating to disabilities caused by particular chronic diseases as well as general measures, strategies and recommendations common to the prevention of all disabilities caused by chronic diseases.

This report does not attempt to provide an exhaustive list of all possibilities of preventive action. This would be impossible, given the large number of chronic diseases and the very different types of disabilities among individuals. This report does intend, however, to use examples of chronic diseases in order to reduce disabilities faced in everyday life and also to avoid participation restrictions which could follow.

Chronic diseases with both high and low incidence were taken into account. It will also be demonstrated that preventive action is necessary regardless of the age of the person concerned and that diseases that have physical as well as mental consequences have to be considered.

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[1] A more detailed discussion of the definition of the term "prevention" is included in Appendix 2 to this report.

2. Working methods

The report was elaborated by the Council of Europe Committee of experts on the prevention of disabilities linked to chronic diseases (Partial Agreement) (P-RR-PREV) between June 2001 and September 2003.

As a first step, the committee agreed on working definitions of the terms “chronic diseases” and “prevention”.

With the aim of focusing on full participation and inclusion of people with chronic diseases and taking a comprehensive view of the situation, the committee chose an approach covering all aspects of living with a chronic disease. This made it possible to avoid a too “medical” and/or too technical approach.

As a second step, the committee adopted an illustrative, non-exhaustive list of chronic diseases. The examples were chosen not according to the seriousness of the public health problem but because, apart from their primary or secondary prevention aspects, it seemed that some useful lessons could be learned from them regarding possible measures to prevent restrictions on participation in society. The examples were:

1. dementia;
2. schizophrenia;
3. frontal lobe syndrome;
4. persistent vegetative state;
5. pauci-relational state;
6. diabetes;
7. obesity;
8. asthma and COPD (chronic obstructive pulmonary disease);

9. colorectal cancer;
10. breast cancer;
11. multiple sclerosis and amyotrophic lateral sclerosis.

The impact of each disease was considered with reference to:

a. everyday, basic life;
b. home life;
c. family life;
d. schooling and training;
e. leisure, culture, sport;
f. transport and movement;
g. public facilities, residential provision, housing;
h. life in society;
i. working life;
j. access to health care, particularly the financial aspects;
k. physical access.

To ensure that national delegations' contributions were as clear and complete as possible and allow comparison of them, delegations were asked to produce standardised information in the form of three tables:

- Table I showing the "difficulties or disadvantages";
- Table II showing the "responses existing in each country aimed at alleviating disadvantages";
- Table III setting out "proposals for measures aimed at curbing disadvantages".

With a view to involving users these lists were also sent to the European Disability Forum, representatives of which attended a hearing with the committee.

In the light of the analysis of the information contained in the tables provided by delegations, the committee drafted general and specific measures and strategies to fight against any possible disadvantages suffered by persons with chronic diseases and to enable them to fully participate in society. The final stage consisted of the drawing up of recommendations.

Grid used for tables

Life situations	Chronic disease										
	1. dementia	2. schizophrenia	3. frontal lobe syndrom	4. persistent vegetative state	5. pauci-relational state	6. diabetes	7. obesity	8. asthma and COPD (chronic obstructive pulmonary disease)	9. colorectal cancer	10. breast cancer	11. multiple sclerosis and amyotrophic lateral
a. everyday, basic life											
b. home life											
c. family life											
d. schooling and training											
e. leisure, culture, sport											
f. transport and movement											
g. public facilities, residential provision, housing											
h. life in society											
i. working life											
j. access to health care, particularly the financial aspects											
k. physical access											

3. Profile of specific needs of people with potentially disabling chronic diseases

3.1. Introduction

People with chronic diseases need first and foremost health care follow-up, and most of the time also social support services. The unstable nature of chronic diseases and the subsequent psychological burden on the individual, partner, family and friends are also specific problems to be faced. This profile of specific needs is directly related to the chronic disease. Additional disadvantages may become evident when their environment and society at large are incapable of responding and adjusting to the specific needs of people with chronic diseases. They may encounter difficulties in addition to their disease. Another disadvantage is related to the fact that it is often not immediately obvious or visible that a person has a chronic disease and may encounter disabilities linked to that disease. Usually people with chronic diseases do not see themselves as disabled persons and do not want to be labelled or categorised that way. This can be a complicating factor when people with a chronic disease become dependent on provisions and services and that are mainly geared to the needs of people with disabilities.

The committee is offering the following non-exhaustive list of chronic diseases:

Examples of chronic diseases

1. Mental and behavioural diseases
    - Dementia
    - Schizophrenia
    - Frontal lobe syndrome

2. Diseases of the neurological system
    - Multiple sclerosis
    - ALS
    - Persistent vegetative and pauci-relational state
3. Pulmonary Diseases
    - Chronic obstructive lung disease
    - Asthma
4. Metabolic, nutritional and endocrinal diseases
    - Diabetes
    - Obesity
5. Tumoral diseases
    - Breast cancer
    - Colorectal cancer

3.2. Mental and behavioural diseases

3.2.1. Dementia/Alzheimer

a. *Definition and short introduction*

The term "dementia" refers to a range of symptoms commonly found in people with brain diseases. The most common causes are:

- disruption of the cerebral blood circulation as a result of numerous minor cerebral vascular accidents (vascular dementia); and
- deposition of pathological proteins in the brain cells as a result of metabolic disruptions (Alzheimer's disease).

Vascular dementia accounts for about 15% of all cases of dementia, Alzheimer's disease for more than 50%. All other cases are less common forms of dementia.

Dementia occurs in all degrees of severity. In cases of slight dementia, patients are still able to manage everyday life on their own. The main symptom is forgetfulness. Patients encounter problems with difficult and new tasks. Cases of medium severity of dementia require constant supervision by others, as the patient may encounter dangerous situations when dealing with water or electricity, for example. Temporal and spatial orientation is affected. In cases of severe dementia, linguistic skills as well as spatial and temporal orientation are lost entirely. Patients no longer recognise their relatives. The final stage is absolute helplessness.

The incidence of the disease increases strongly with age. In cohorts aged 65-69, prevalence is 1.2%. This prevalence doubles every 5 years, reaching about 24% in cohorts aged 85-89. A small percentage of cases of dementia are treatable or potentially reversible, but in the vast majority of cases it is only possible to prolong the course of the disease. In Germany alone, an estimated 900,000 people have dementia of high or medium severity. The total cost per year and per patient was stated to be 47,000 euros, of which clearly more than half is paid to the families.

Care for patients with dementia presents a special challenge to all European countries, as:

- the number of older people is increasing over proportionally in all countries,
- the duration of the disease is 8 years on average, and
- families are often overburdened by caring for the patient and seek professional help.

b. *Specific difficulties and disadvantages*

1. Lack of acceptance or awareness of the disease on the part of the patient.
2. Problems conducting one's life autonomously as a result of forgetfulness.
3. Problems with temporal and spatial orientation, resulting in running away ("I have to go to work") or getting lost in familiar surroundings.
4. Problems recognising familiar people.

5. Anxiety and hallucinations, sometimes in connection with actual or verbal aggressiveness.

6. Growing isolation as relatives and friends back off.
7. Disturbed day/night rhythm (nocturnal restlessness).
8. Malnutrition.
9. Increased accident risk.
10. Decreasing medical care with increasing severity of the disease.

c. *Specific measures*

1. Development of rehabilitation programmes aimed at using and maintaining existing skills and structuring daily routines.
2. Development of health care programmes providing adequate care also for people with dementia.
3. Formation of patient groups who live together or are cared for together and in which social contacts are offered that create greater stability.
4. Creation of an environment which accounts for the specific disadvantages encountered due to the disease, for example, facilitating orientation, promoting social contacts and considering the increased accident risk.
5. Relief for care-taking relatives provided by advice centres and arrangement of professional help for periods of vacation or illness, additional support in crisis situations.
6. Care-giving courses for care-taking relatives on how to deal with the patient.
7. Training and continuous education of care-takers with geriatric psychological expertise.

3.2.2. Schizophrenia

a. *Definition and short introduction*

Life with schizophrenia is marked by a lack of homogeneity and order in all psychological processes and the inability to understand oneself as a homogeneous person.

Schizophrenic disturbances are more or less far reaching disruptions of the overall personality. They usually do not concern individual psychological functions alone, but they affect the patient's experience and behaviour in their entirety. Among others, this includes:

1. Thinking, where disturbances may occur in the way of thinking (for example, confusion) and as to what is being thought (for example delusions).
2. Emotions: typical symptoms are inappropriate emotions, ambivalence, instability.
3. Perception (there may be disturbances in the sense of vision, hearing, smell and touch).
4. Awareness of one's body. Disturbances can be manifold.
5. Behavioural disturbances: the variety of disturbances affects the patient's behaviour which may seem strange, bizarre, unpredictable. States of agitation or inhibition, going as far as immobility, may be encountered.
6. Self-perception: is often disturbed. Patients perceive themselves as strangers. No single one symptom is specific for schizophrenia on its own. Nor is any single symptom specific to the diagnosis.

The most common symptom by far is a lack of acceptance or awareness of the disease, as the International Pilot Study of Schizophrenia, directed by the WHO, concludes. Among 800 patients with acute schizophrenia, the following percentage encountered the indicated symptoms:

• lack of acceptance/awareness of disease	97%
• acoustical hallucinations	74%
• obsessive behaviour with regard to relationships	70%
• flattened emotions	66%
• paranoia	64%

The diagnosis of schizophrenia is thus based on the identification of a "pattern" of – individually seen – unspecific symptoms which, if occurring together, are typical of the disease.

All publications point to the special vulnerability of persons suffering from schizophrenic disturbances.

b. *Specific difficulties and disadvantages*

1. Disturbances in the way of thinking.
2. Linguistic disturbances.
3. Perceptive disturbances.
4. Emotional disturbances.
5. Motor disturbances.
6. Difficulties concentrating.
7. Low stamina.
8. States of agitation.
9. Reduction of social contacts.
10. Inactivity.
11. Strongly varying levels of motivation.
12. Mood swings.
13. Strongly varying capacity to perform.
14. Insecurity in prognostic self-assessment.
15. Interpersonal problems.

c. *Specific measures*

1. Early and comprehensive individual intervention plans.
2. Psychological educational measures to promote self-management.
3. Support in the patient's social surroundings, usually at the place of residence.
4. Offers to structure daily routine, either with or without offers to work.
5. Offers of individually adjustable levels of work for several hours or full days.
6. Long-term professional guidance, as it often takes a long time until a state of stability is reached.
7. Planning, co-operation and co-ordination with regard to all complex support offers provided by the regional care institutions, mostly the local authorities.
8. Entitlement to professional case management.

3.2.3. Frontal lobe syndrome

a. *Definition and brief description*

This heading covers the consequences of head injuries (and acquired brain damage with similar consequences), which are mainly:

- cognitive;
- psychological/behavioural, often grouped together under the term "frontal lobe syndrome";
- neuro-motor or neuro-sensory.

Clinically, the picture is of varying severity, and may go so far as multiple handicaps or even a persistent vegetative state or pauci-relational syndrome. Here we shall deal only with the disorders that come under the heading of "frontal lobe syndrome". They include behavioural disorders with personality changes (apathy, introversion, emotional blunting, aloofness, irritability, personality disorders, loss of inhibition, etc.), emotional and relational problems (attention, concentration, proneness to intellectual fatigue, memory, difficulty in planning, etc.) and difficulty in sleeping. Patients tend to deny their problems and consequently generally overestimate their capacities, with the result that they are demanding and angry about the difficulties encountered and their failures, and may even think they are being persecuted.

b. *Special difficulties and handicaps*

1. These disorders may go unrecognised by professionals and patients alike and be under-diagnosed, and may therefore not be properly treated either in the early stages, shortly after the damage occurs, or in the long term.
2. Because of frequent problems in planning and carrying out everyday tasks, it may be necessary for a third person to stimulate, monitor and supervise the brain-damaged person. This dependence on a third person may be total in the most serious cases.

3. Under-estimation of these needs and of functional dependency during expert appraisals may have social and financial consequences.
4. Little account is taken of the deterioration of relations within the family (emergence of a “new personality”, emotional suffering of family members, possible need to take over the role of the family, burden resulting from the patient’s dependency, complete family upheaval, etc.).
5. There are often major problems in adapting at work, particularly because of relational difficulties and neuro-psychological disorders, in particular cognitive and behavioural disorders, which often result in patients’ having to stop work for good.
6. Generally speaking, social rehabilitation after hospitalisation is highly problematical and necessitates specific measures.
7. There are insufficient medical, psychological and social support facilities after hospitalisation, but such support is necessary throughout the life of the individual (support at home, day centres, socio-occupational rehabilitation in a suitable environment, and so on). In the most serious cases (complete loss of the ability to perform common everyday tasks and social autonomy), there may be a need for permanent or intermittent sheltered housing supervised by specialist staff.

c. *Specific measures*

Given the particular effects of frontal lobe syndrome and brain damage caused by injury, the following specific measures are suggested to prevent handicaps relating to these diseases:

1. Special interdisciplinary rehabilitation programmes covering motor, cognitive, socio-behavioural and psycho-emotional aspects.
2. Structured, long-term multidisciplinary post-hospital (medical and social) support of various kinds: assessment,

rehabilitation, socio-occupational retraining, family support, social support, day centres, sheltered housing, etc.

3. Special training for experts responsible for assessing the disability and arranging for legal compensation.
4. Special support for family members, in particular the partner and children.

3.3. Diseases of the neurological system

3.3.1. Multiple sclerosis and motor neurone disease

a. *Definition and brief description*

Both these illnesses are progressive diseases of the nervous system. They cause disorders which gradually worsen over time, in particular paralysis, which eventually becomes generalised. Depending on the disease concerned and on the patient, this may be combined with muscle contractions, spontaneous movements, lack of motor co-ordination, speech difficulties or loss of speech, swallowing difficulties or loss of the swallowing reflex, visual disturbances, sensory symptoms, loss of bladder control and impaired respiratory function. Motor neurone disease inevitably progresses, leading to the death of the patient within three years on average. The main features of these diseases are therefore their progressive nature (they evolve more or less rapidly), the combination of physical (motor, visceral and sensory) disorders and an increased functional dependency.

b. *Specific difficulties and handicaps*

There is a gradual loss of function in the following respects, until the situation becomes pathological:

1. Walking, body movements, the ability to grasp objects.
2. Standing, holding up the trunk and head when sitting.
3. Speech and ability to write.

4. Independence as regards mobility in the community, then mobility at home and elementary mobility (when lying down at night, for example).
5. Independence in respect of social activities, activities in the home and the elementary tasks of daily life, in particular hygiene, feeding and satisfying excretion needs.
6. Respiratory autonomy.

There are difficulties as regards access to the technical aids and human assistance needed.

Families face a special burden and suffer particularly, firstly because the patient is so heavily dependent and secondly because the disease steadily worsens. The coexistence of motor disorders and communication difficulties makes for social isolation. There are ethical questions as regards whether vital functions, in particular feeding and breathing, should be artificially sustained. The main problem is to reconcile the need to compensate for what are sometimes major disabilities with the desire, frequently expressed by patients, to remain in their own homes.

c. *Specific measures*

Given the particular effects of multiple sclerosis and motor neurone disease, the following specific measures are suggested to prevent handicaps related to these diseases:

1. Recognition as long-term illnesses and, consequently, reimburse- ment of the cost of care in full.
2. Access to rehabilitation measures in their life environment (by occupational therapists).
3. Continued support and counselling for the individual and his/her family.
4. Fostering an awareness among the authorities responsible for the administrative processing of files so that procedures can be adapted to take account of the rapidly progressive nature of the diseases.
5. Improving access to technical aids, and the funding of such aids.

6. Improving access to human assistance, and the funding of such assistance.
7. Combating environmental factors that add to the handicap, particularly as regards mobility (driving, public transport, access to buildings, etc.).
8. Ethical supervision of decisions as to whether artificially to sustain failing vital functions.

3.3.2. Persistent vegetative state and pauci-relational state

a. *Definition and brief description*

If the brain is seriously affected by, for instance, injury, lack of oxygen or metabolic factors, prolonged coma may result. The coma phase ends when the patient opens his or her eyes. This is the start of what is known as the "vegetative" phase, during which the patient can live independently in vegetative terms (without artificial ventilation), has waking and sleeping cycles but cannot relate to or interact with his or her surroundings. The patient does not seem conscious. How this phase progresses depends on the patient: some progress more or less quickly towards a state of consciousness and an ability to relate, while others remain unable to relate. After a period, the length of which depends on the nature of the incident that caused the coma, continuation of this state in which the patient is unable to relate justifies the use of the term "persistent vegetative state". In fact, in the case of most of these patients, those looking after them eventually detect a minute capacity for voluntary reaction (movement of a finger, for instance) in response to an environmental stimulus – an unreliable and intermittent reaction; one then talks of a pauci-relational state.

b. *Specific difficulties and handicaps*

1. Total and absolute dependence for survival, 24 hours a day.
2. Permanent need for a nursing environment.
3. Total absence of initiative.

4. Risk of premature diagnosis and that re-education and rehabilitation will be stopped too soon.
5. Lack of adequate solutions both in a medical environment and at home.
6. Suffering on the part of family members on account of the lack of any possibility of human exchange, the major burden the patient represents and the lack of any prospects of an improvement in the situation.

c. *Specific measures*

Given the particular effects of a persistent vegetative state and a pauci-relational state, the following specific measures are suggested to prevent handicaps relating to these diseases:

1. Recognition as long-term diseases and, consequently, reimbursement of care in full.
2. Recognition of the absolute need for round-the-clock care and assistance.
3. Provision of a genuine choice of living environment (at home or in an institution).
4. Preparation of a specific care and support plan for the person concerned and members of the family.

3.4. Pulmonary diseases

These are diseases of one or several organs (circulatory, respiratory, digestive system, etc.) with the exception of diseases and systems mentioned in other categories (see ICD, the WHO International Classification of Diseases)

Typical example:

3.4.1. Chronic obstructive lung disease (COLD)

a. *Definition and brief description*

This disease is defined by a reduction in expiratory flow rates, which is not totally irreversible. This reduction is generally progressive, and is linked to inflammation of the secondary airways caused by harmful particles or gases. COLD frequently takes the form of chronic bronchitis.

As it develops, the disease often results in ineffective respiration, i.e. a fall in the blood’s oxygen content (respiratory insufficiency) which may eventually affect the heart.

In France, for example, COLD affects two and a half million people, and over 15,000 die each year from its complications. More men than women contract it, but increased smoking among women is tending to level the difference.

In 90% of cases, smoking is the main cause of the disease, and 20 to 30% of people who smoke more than 20 cigarettes a day will suffer from it.

Other causes include exposure at work to contaminants such as toxic gases, solvents, mining products, and silica dusts.

One of the main symptoms is shortness of breath on exertion, or dyspnea.

b. *Specific difficulties and handicaps*

1. School absenteeism.
2. Retardation at school.
3. Work absenteeism.
4. Limited ability to do sports.
5. Restrictions linked to the treatment.
6. Need to give attention to the environment (avoid contact with allergens).

c. *Specific measures*

1. Involving mutual aid associations.
2. Ensuring 100% coverage of serious respiratory insufficiency as a long-term illness.
3. Health education, particularly for child patients: learning about taking medicines and preventing and treating acute attacks, etc.

4. Improving schooling conditions for asthmatic children, including a health education module in teacher training courses.
5. Heightening public awareness by including health education among the general curricula.
6. Removing restrictions for practising sports.
7. Ensuring that employment regulations are non-discriminatory in terms of access to work and provide protection in cases of the inevitable absenteeism caused by the disease.
8. Reinforcing anti-smoking regulations in both public areas and workplaces.
9. Introducing systems for monitoring air pollution levels for public information, and adopting motor traffic restrictions in towns and cities.

3.4.2. Bronchial asthma

a. *Definition and brief description*

Asthma affects all age groups, but often starts in childhood. It is marked by recurrent crises, when the patient suffers from respiratory difficulties and wheezing, which vary in seriousness and frequency from one person to another.

The main risk factors are exposure, especially in early childhood, to allergens in the home (for example, dust-mites, cats, cockroaches) and a family history of asthma or allergies. Exposure to tobacco smoke, and to chemical irritants at work, are other risk factors.

There are 100 to 150 million asthmatics in the world, and the number is increasing. Every year, more than 180,000 people die from the disease.

Experts are trying to account for a 50% rise in the incidence rates (taking the global average figure) every ten years. Part of the increase is certainly due to the fact that many cases used to go unreported, and to the reclassification of chronic illnesses, but certain specialists are convinced that there is "something" out there in the environment, which is linked with development and industrialisation, and is fuelling the increase.

Being a chronic condition, asthma usually requires ongoing medical care. Medicines are not the only answer. It is also important to avoid anything that may trigger a crisis, as well as stimulants that irritate and inflame the respiratory tract and aggravate the asthma.

b. *Specific difficulties and handicaps*

1. School absenteeism.
2. Retardation at school.
3. Work absenteeism.
4. Limited ability to do sports.
5. Restrictions linked to the treatment.
6. Need to give attention to the environment (avoid contact with allergens).

c. *Specific measures*

1. Involving mutual aid associations.
2. Ensuring 100% coverage of serious respiratory insufficiency as a long-term illness.
3. Health education, particularly for child patients: learning about taking medicines and preventing and treating acute attacks, etc.
4. Improving schooling conditions for asthmatic children, including a health education module in teacher training courses.
5. Heightening public awareness by including health education among the general curricula.
6. Removing restrictions for practising sports.
7. Ensuring that employment regulations are non-discriminatory in terms of access to work and provide protection in cases of the inevitable absenteeism caused by the disease.
8. Reinforcing anti-smoking regulations in both public areas and workplaces.

9. Introducing systems for monitoring air pollution levels for public information, and adopting motor traffic restrictions in towns and cities.

3.5. Metabolic, nutritional and endocrinal diseases

These are diseases of the metabolism, i.e. the chemical and physio-chemical changes that take place in all the organism's tissues and so affect several organs.

Some typical examples:

3.5.1. Diabetes

a. *Definition and brief description*

Diabetes is a chronic disease, and is due either to a genetic or acquired deficiency in insulin production by the pancreas, or to the fact that this insulin is not sufficiently active. This deficiency leads to an increase in blood sugar levels, in turn causing lesions which affect several systems, especially the blood vessels or nerves.

There are two main types of diabetes:

- **Type 1,** which used to be known as insulin-dependent diabetes. The pancreas is unable to produce the necessary insulin. This form is commonest in children and adolescents, but is increasingly being diagnosed in adults.
- **Type 2,** which used to be known as non-insulin-dependent diabetes, results from the organism's inability to react correctly to the effects of the insulin produced by the pancreas. This type is much commoner, and accounts for about 90% of all cases at global level. It mainly affects adults – but increasingly adolescents too.

WHO has called diabetes the next global epidemic. Recent data suggest that, if current trends continue, the number of diabetics will more than double in the next 25 years, from 140 to 300 million. The increase will mainly affect the developing countries, and be due to demographic growth, population ageing, unbalanced diet, obesity and sedentary lifestyles.

In 2025, most diabetics in the developed countries will be over 65, while most diabetics in the developing countries will be in the most productive age group, 45 to 64.

The most serious complications are retinopathy, renal insufficiency, heart diseases, neuropathies and "diabetes foot".

Even in developed countries, many diabetics who need care do not receive it, mainly because too little information is provided for the public and for health care professionals.

As regards primary/secondary prevention, recent studies in Finland and the United States have shown that the onset of diabetes can be prevented or delayed in obese subjects with a moderate intolerance to glucose.

Even modest weight loss and a daily half-hour walk are enough to reduce the incidence of diabetes by over 50%.

b. *Specific difficulties and handicaps*

1. Need to follow a strict diet.
2. Restrictions linked to the treatment.
3. Need for family to adapt.
4. Can only have limited exercise.
5. Difficulties in obtaining a driving licence.
6. Difficulties in obtaining an insurance policy.
7. Discrimination at the workplace.

c. *Specific measures*

1. Providing health education for society in general and for diabetes sufferers in particular, with a view to making them self-reliant, particularly child patients: learning about metabolic control, nutritional rules, etc.
2. Training family members in assisting patients, particularly where metabolic control and information on any complications in the illness are concerned.

3. Involving associations of patients' families and other mutual aid associations.
4. Ensuring 100% coverage of this disease as a long-term illness.
5. Providing additional information for teachers with a view to improving education for diabetic children, including a health education module in teacher training courses.
6. Removing restrictions on access to loans and insurance policies (as in the case of other chronic diseases).
7. Intensifying chiropodial monitoring, stressing its preventive role in avoiding any trophic complications.
8. Running diabetes scanning campaigns, notably among the elderly.
9. Applying the European Union criteria for obtaining and retaining a driving licence.
10. Ensuring that employment regulations are non-discriminatory in terms of access to work and provide protection in cases of disease-related complications.

3.5.2. Obesity

a. *Definition and brief description*

In medical terms, obesity is an excess of fat with harmful effects on health. Fat is assessed on the Body Mass Index (BMI), which takes account of weight and height: weight in kilos, divided by the square of height in metres.

A BMI of 25 and over indicates that a person is overweight; a BMI of 30 and over indicates obesity. Obesity is moderate when the BMI is 30 to 34.9, serious when it is 35 to 39.9, and very serious when it is 40 or over.

Obesity is a disease, since it damages health. Its effects are wide-ranging, and can be physical, psychological or social:

- physical: diabetes (type 2), hypertension, sleep apnea, etc.;
- psychological: depression, negative self-image, etc.;

- social: discrimination, isolation, etc. Obese people are stereotyped as being unhealthy, academically ungifted and socially awkward.

Excess weight and obesity are considered major problems. In France, for example, 9.6% of adults and 12% of children are obese.

Several studies have looked at the growth in the prevalence of childhood obesity over several years, and the results are alarming. For example, the figures have increased 2.3 to 3.3 times over 25 years in the United States, 2 to 2.8 times over ten years in the United Kingdom, and 3.9 times in Egypt. We can therefore speak of an epidemic of childhood obesity, especially – but not only – in the most developed countries.

Various causes have been adduced for the increase: genetic factors, bottle-feeding of babies, lack of exercise, high consumption of energy-rich foods (particularly during long spells in front of the television, which carries frequent commercials for just this type of food), environment and family habits. A recent article on this problem in The Lancet uses the telling phrase, “toxic environment”.[1]

b. *Specific difficulties and handicaps*

1. Limited ability to do sports.
2. Discrimination at the workplace.

3.6. Tumoral diseases (e.g. breast cancer and colorectal cancer)

a. *Definition and short introduction*

The term cancer of the breast or colorectal cancer is given where there is evidence of neoplastic change affecting breast, colorectal or rectum. They are coded as C18, C19, C20 (colorectal and rectum) and C50 (breast) according to the

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[1] Reference: The Lancet, vol 360, 10 August 2002, 473-482 (Seminar: Childhood obesity: public-health crisis, common sense cure).

International Statistical Classification of Disease and Related Health Problems, World Health Organization.

Breast cancer

Breast cancer is a malignant growth that begins in the tissues of the breast. Cancer of the breast is the most commonly occurring cancer amongst women comprising 20 to 25% of all malignancies in women in Europe and 18% of all female cancers worldwide. Over a lifetime, one in eight women are diagnosed with breast cancer.

There are different types of breast cancer. Ductal carcinoma begins in the cells lining the ducts that bring milk to the nipple and accounts for more than three quarters of breast cancer. Lobular carcinoma begins in the milk-secreting glands of the breast but is otherwise fairly similar in its behaviour to ductal carcinoma. Other varieties of breast cancer can arise from the skin, fat, connective tissues, and other cells present in the breast.

Figures from EUCAN, 1995, show an incidence of 199,091 cases amongst women living in the European Region.

Colorectal cancer

The colorectal and rectum are part of the large intestine (bowel). Colorectal and rectum cancers, which are sometimes referred to together as “colorectal cancer”, usually grow in the lining of the large intestine.

Cancer of the colorectal and rectum accounts for 11% of cancer deaths. It is the third most common cancer in adults. It accounts for 9.4% of incident cancers in males and 10.1% in females. Figures from EUCAN, 1995, show an incidence of 198,199 cases in the European Union.

It is important when talking about tertiary prevention of these conditions (cancer treatment; curative, palliative and rehabilitation) that all treatments are evidence-based with the purpose of increasing both quality and length of life. There is a need for multidisciplinary input, early recognition of treatment related adverse effects and provision of a seamless service from hospital, community, hospice and primary care.

b. *Specific difficulties and disadvantages*

1. Pain and recurrence of disease can interfere with ability to work and to carry out activities of daily living.
2. Appropriate modality of care must be provided with the aim of decreasing impact on home life and employment.
3. Need for recognition that treatment may cause side effects such as the occurrence of further disability, neutropenia, and malabsorpsion. These side effects need to be anticipated, recognised early and appropriate treatment given.
4. Psychological impact of disease particularly in breast cancer can impact on quality of life.
5. There may be a specific need for aids and appliances such as stoma care and prosthesis.

c. *Specific measures*

Due to the particular consequences of both breast and colorectal cancer the following specific measures are proposed to prevent disability

1. Ensuring greater awareness and use of disability rating scales and greater understanding of the impact of the disabling effects of the disease on the individual in everyday life.
2. Reinforcing pain treatment networks, improving access to pain relief and pain treatment centres.
3. Ensure equity of access to treatment and supportive care by subsiding medical costs.
4. Provision of self-help groups.
5. Easy availability of aids and appliances.
6. Legislation to protect employment.
7. Provision of information for patients and their families.

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4. Specific measures to prevent disabilities linked to chronic diseases

4.1. General policy framework for specific measures

People with potentially disabling chronic diseases are not a homogenous group but individuals who require long-term or intermittent cure/care provisions, specific forms and different levels of services and support. They can benefit to a large extent from measures and services which fall within already existing general disability policy provisions. The responsibility for disability policy is quite complex. Areas for special attention regarding disability such as health care, care, technology, housing, education, employment, mobility and recreation, are in most countries the responsibility of different governmental sectors local authorities and private enterprise.

Concerted government action is needed to develop viable policies on equal treatment, accessibility, inclusion and community living for people with potentially disabling chronic diseases. To be able to achieve effective and enduring policy schemes, authorities in charge should implement policy programmes that promote that all sectors of society take into account the needs of people with potentially disabling chronic diseases. Mainstream solutions should be complemented by providing expert centres and specific support services for people with chronic diseases. Legislation on equal treatment should enhance social inclusion and improved access to all public facilities and specific services.

National policies should also use principles of universal design to improve accessibility by removal of all kinds of physical barriers. Technology can also play an important role in helping people with potentially disabling chronic diseases to participate fully in society. Especially the application of new assistive technology at home can ameliorate disabilities linked to chronic diseases and open new possibilities to live independently in the local community. The opportunities of modern information communication technology (ICT), and in particular the use of Internet, can promote the exchange of chronic disease-specific and practical information, make it possible to work at home and alleviate social isolation.

Opportunities for full participation and inclusion are created by living in the community and by providing equitable access to community-based services. Access to specific services should be based on professional individual diagnosis and independent assessment of needs. Governments should develop programmes geared to tailor-made care and service delivery, for example individualised funding (personal budgets). Governments should consult on a regular basis with umbrella organisations of and for people with potentially disabling chronic diseases to create a broad base support for government policy and to facilitate implementation of policy programmes. There is wide range of chronic diseases and chronic disease specific client organisations. These organisations should be supported. But they should also combine forces and resources and work together to have a maximum impact in supporting the individual and families and monitoring policy programmes and the quality of support services.

In general people with potentially disabling chronic diseases are dependent on daily and long-term care and support and have a consequently vulnerable position with respect to service providers. Therefore policy schemes on quality control of services should be pursued by governments and service providers within a framework of striving for quality of life. People with potentially disabling chronic diseases as clients of care and public services should play an important role regarding the development, assessment and evaluation of the quality of services. A broader concept of quality of life, that is dependent on a comprehensive array of different services and support, must be safeguarded.

Families are confronted on a day-to-day basis with the continuing responsibility of care and support of family members with chronic diseases and/or disabilities. Caring work is physically, psychologically demanding and the pressures of this work can lead to illness and depression. Respite care services can offer temporary relief from the continual stresses of care giving. Moreover families with a family member with a chronic disease are confronted with a accumulation of extra (medical, living) costs that often will often have a negative impact on their financial security and increase social isolation. Family organisations and organisations of informal carers should have easy access to centres of excellence, practical information and independent advocacy.

Within the local community and within their own personal, environment people with potentially disabling chronic diseases should be able to receive the support they need within the existing regular structures of health care, housing, education, employment, social services and transport. Comprehensive professional communal services and expert centres must be in place to cope with specific problems and emergencies.

Special attention should also be paid to public awareness-raising. To have lasting effects, there should be communication strategies to provide relevant information about chronic diseases and its consequences. Purposeful campaigns in the media can improve the image of and focus on the capabilities of people with potentially disabling chronic diseases.

4.2. Specific measures

4.2.1. Introduction

People with chronic diseases make a specific demand on health care, medication, assistive technology devices and social services. To cope with their problems and to be able to function in society, they need all kinds of specific measures concerning the individual, family and carers, professionals, society and government.

4.2.2. Measures concerning the individual

1. Access to diagnosis as early as possible and its announcement accompanied with appropriate measures.
2. Access to information about the disease and social resources/networks.
3. Access to competent health care.
4. Access to rehabilitation measures.
5. Access to quality social services.
6. Access to adequate economic support and benefits.
7. Access to functional compensation solutions.
8. Psychological support relating to the acknowledgement and fluctuation of the disease and the uncertain life expectation.
9. Right to choose one's lifestyle.

4.2.3. Measures concerning the family and carers

1. Announcement of diagnosis accompanied by appropriate measures.
2. Health information about the disease and on the situation of the person concerned.
3. Promotion of the actual (voluntary) help of families, close relations, family associations or other appropriate NGOs, reinforcement of family associations, self-help groups and mutual aid associations, training of families and close relations, and promotion of their know-how and expertise.
4. Social resources/networks and respite/relay without negative financial consequences.
5. Services and support for family carers for example, respite services and reconciliation of professional and private life.
6. Psychological support relating to the acknowledgement and fluctuation of the disease and the uncertain life expectation.

4.2.4. Measures concerning professionals (health care, rehabilitation, social services, education and other public administrations)

1. Multidisciplinary training of professionals (continuing and up-to-date) taking into account of social and environmental dimensions of chronic diseases and of those measures that have a social impact.
2. Promotion of the acknowledgement of the disease.
3. Offering to professionals a technical datasheet relating to the disease, its treatment and the psychological support of the individual and the family.
4. Granting psychological support to professionals to avoid the burn-out syndrome induced by the chronic nature of the disease.
5. Co-ordination and exchange of information within and across health care and rehabilitation institutions and disciplines, as well as within and across public administration at all levels.
6. Setting up professional resource centres for information and training.
7. Promotion of the ability to adapt interventions to the fluctuating nature of the disease.
8. Swift response from public administration bodies taking into account the uncertain evolvement of the disease.
9. Multidisciplinary and cross disciplinary approach, co-ordination and exchange of information within and across all professional levels.

4.2.5. Measures concerning society and government

1. Provision of social services for example, home help, housing services (service accommodation), institutional care, meals on wheels, transportation services, alterations of the dwelling and adding new technology.
2. Promotion of public awareness on the existence, impact, long-term effect, health and social consequences of chronic diseases, notably the risk of social exclusion, by regularly giving relevant thorough information.

3. Promotion of acknowledgement, understanding and flexibility by society at large and as early as possible, based on the principle of non-discrimination on the grounds of disease and/or disability, taking into account that:
   - the evolvement of the disease fluctuates;
   - the diseases or disability may not be visible;
   - the diseases can be life threatening.
4. Providing and enhancing access to the built environment, transport, assistive technology, health care, rehabilitation, (adaptable) housing, education, employment, information and leisure activities (including culture and sport). This can be achieved through for example standardisation, harmonisation and Universal Design.
5. Reinforcement and extension of professional home care, including help in professional and social integration, in order to enable the person with a disability to choose his/her care setting, and to prevent and/or delay institutional care as much and as long as possible, if he/she so wishes.
6. Development of neighbourhood facilities for the co-ordination of care and services at all levels, notably by using an inter-disciplinary approach in the field of health care and services at community level.

5. Strategies to prevent disability and enhance quality of life

5.1. Introduction

The basic principle that people with chronic diseases are citizens with full human rights includes the right to appropriate health care, social welfare and other public services. These are vital elements to realise quality of life. As illustrated in Chapter 4, people with chronic diseases are dependent on all kinds of specific services and support. Therefore a holistic approach is needed that is based on existing services and expertise to be able to respond adequately to the needs of people with chronic diseases and their relatives.

Individual multidisciplinary assessment of needs is the starting point in this holistic approach and can enhance the fine-tuning of services and support. Different kinds of specific measures should be linked to form a comprehensive, accessible and community-based system of services ("community linking"). Integrated and co-ordinated service provision can effectively support strategies aimed at preventing disabilities and handicaps, sustain community living and enhance quality of life.

5.2. Early intervention and screening

5.2.1. General considerations

To successfully apply measures to prevent disabilities and handicaps linked to a chronic disease, accurate and early recognition of the disease and the possible disabling effects of that disease is necessary for people of all ages. Disability may arise from prenatal and postnatal infections (for example, Aids, tuberculosis), endemic diseases, prenatal genetic diseases and chronic diseases caused by environmental factors (for example, pollution) or genetic pre-disposition. Neonatal screening makes it possible to diagnose specific disorders and to early identify a disabling condition.

The family in particular can also play a significant role in the early detection of disabilities. If a person is diagnosed as having a chronic disease that may lead to a disability, then proper intervention programmes and prompt treatment can be started at an early stage and can help ameliorate the effect of the chronic condition, prevent disabilities and reduce negative consequences and the burden on the family. It may also prevent hospitalisation and dependency on long-term (institutional) care.

Children and young adults with chronic conditions and their families should be supported to meet their specific needs pertaining to a comprehensive array of services including early detection and intervention, early aid, education and advocacy in order to help them to have a normal life.

5.2.2. Gerontological considerations

Preventive care programmes dependent on a specific age group (e.g. 65-74, 75+) are recommendable and should include regular screening of chronic diseases to be able detect the onset of disabilities before they become irreversible.

Comprehensive geriatric assessment is a way of screening problems in the elderly and may contribute to obtain an accurate picture of the person’s ability to function in daily life and to develop strategies to prevent disability and reduce the need for institutionalisation.

Preventive measures should be aimed at minimising the discomforts from chronic conditions and prolonging the period of activity and ability of the elderly to live independently in the community and to avoid or postpone institutionalisation.

To reduce reliance on institutional care alternative settings are needed where the elderly can live and receive the care and assistance they need. Assisted living schemes, congregate housing projects, supportive services and home modification are effective ways of supported independent living that enhance quality of life.

Ethical and human rights aspects must be taken into account when older persons are too impaired to manage their own lives. In particular when they are no longer able to speak for themselves and relatives, close friends, or professional may have to ascertain important decisions from them. In these circumstances protection and advocacy programmes (for example carried out by NGOs) can provide for the protection of legal and human rights.

5.3. Home care and domestic support services

Long-term home-based care and domestic support facilities in combination with community-based social services and the application of new technologies, can enhance independent living in the community and prevent or alleviate the disabling effects of chronic diseases. In view of the rapidly ageing population and the increase of older people with chronic diseases on a European-wide scale, there will be a growing demand for professional care at home.

At home recovery from relapses may be faster because of a minimal disruption of the persons' normal life. In case of simple forms of home care family members and relatives or voluntary aides often have a primary responsibility of providing the required assistance. Social welfare policies schemes should be geared to give more structural support to family care givers and voluntary aides.

Case managers linked to rehabilitation and/or expertise centres (see below) could provide professional help and guidance and act as a mediator between the person with a chronic disease who wishes to take his/her own decisions and the often complex network of different services on which he or she is dependent.

The preventive impact of home care and support can be increased if it includes services in the following categories:

- care and support in instrumental (household) activities of daily living (IADL);
- care and support in personal activities of daily living (ADL);
- assistive (medical) technology;
- parent and child care;
- social support and counselling;
- support in medical care (general practitioners).

General practitioners can treat chronic patients at home and play a vital advisory and supportive role in directing chronic patients to either health care (cure) and/or home care services.

Independent living and care by families is often the most appropriate strategy to prevent disabilities and enhance the quality of life. To this end domestic support services and respite resources should be provided. The care to be provided in the home environment may range from traditional support services (ADL) or nursing services, to the application of sophisticated assistive or medical technology devices at home.

In case of complex and severe chronic disorders that require specific interventions or intensive treatment and specialised equipment and facilities, home care and support services are not always sufficient or the most appropriate choice and it would be advisable that hospital provide for outpatient departments (day centres) in order to help them to live at home. When the person is unable to stay at home, alternative accommodation providing for health and social rehabilitation should be offered (for example, sheltered houses, community living).

5.4. Assistive technology

The rapid introduction of new assistive technologies affects the operation of care facilities and services and the welfare of people with chronic diseases. In order to enable the chronically ill in need of cure and care to manage at home, attempts must be made to promote further development of assistive technology (technological aids) to help people remain more independent.

It is of great importance to have the right instruments or technology for proper home care. This concerns both simple medical instruments and technical appliances as well as sophisticated new technologies that make it possible to continue or perform medical treatment at home. A number of medical treatments, now mostly performed in a hospital, can now also be given at home (for example, home dialysis, ventilation, medication delivery devices). In general home care is not yet making full use of these new technologies at its disposal. Only simple, medical- and nursing-technical procedures are being carried out. When the home environment is better equipped and necessary alterations to the home can be made, high quality devices can be obtained in home care versions.

Assistive technologies are also important in relation to all aspects of personal, social and professional life (mobility, communication, active participation in the community, education, etc.) in order to prevent or alleviate the consequences of disabilities. Efforts should be made to ensure that people with potentially disabling chronic diseases can enjoy access to such assistive technologies.

5.5. Community-based rehabilitation

The general aim of rehabilitation is to reverse, reduce or alleviate impairments and disabilities, whether they are congenital or caused by accidents or diseases. Rehabilitation techniques and methods should not only be available in rehabilitation centres, but also in the home environment of the person. Rehabilitation in a real life situation allows to ensure a maximal degree of motivation, application and stabilisation of functional achievements. It also enables family members to be taken into consideration within the rehabilitation process.

People with a chronic disease may be fully independent and functioning in the community when well, but have reduced functional reserve during a relapse and be unable to perform basic activities of daily living (ADL). Periods of illness and/or disability are intermitted by periods of relative good health.

Rehabilitation enables individuals with a chronic condition to extend and improve their periods of (relative) well-being and to reduce the disabling effects of the chronic disease, thereby strengthening physical, mental and social capabilities and improving their quality of life. To be effective the rehabilitation process should be based on a multidisciplinary diagnosis that covers all aspects of the persons' former, current and probable future situation. Community-based rehabilitation is specifically important for people with a chronic diseases with an unstable course who live independently at home.

Individual care plans, careful progress monitoring, specific therapies and preventive care are vital elements in the rehabilitation process. Community based rehabilitation programmes are not only useful and advantageous for people with chronic diseases because their needs can be met within the local community, but also because local rehabilitation services can be linked with other community based services. This promotes co-operation and co-ordination between health care, support and social welfare services and supports independent living. National health centres, expertise centres and institutions can play a role as referral agencies.

To optimise the beneficial effects, the rehabilitation process must be embedded in a multidisciplinary teamwork of physical therapists, occupational therapists, nursing personnel, general practitioners, social workers and of course family members and voluntary aides adopting an interdisciplinary approach.

5.6. Expertise and resource centres

Accessibility of expertise and experiential knowledge about chronic diseases and their disabling effects are key factors in carrying out and upgrading effective strategies and programmes on prevention. This is even more the case with regard to rare diseases.

Promoting expertise starts with gathering and acquiring expertise. In this regard it is important to link scientific research with practical experience. On this basis methodology development can take place. To apply expertise and acquired knowledge in practice it must become embedded in the structure of care giving (health care, home care, community based rehabilitative care). The introduction of protocols and guidelines for diagnosis, assessment, treatment and supervision can help bring this about. Acquired knowledge and expertise should be easily accessible to all interested parties, in particular concerning rare diseases or rare chronic conditions.

In addition to home care and community-based rehabilitative care an interlinked infrastructure of chronic disease expertise centres on a national scale makes it possible to deploy teams of advisers giving ambulatory care and assistance to people with specific needs and problems. People with chronic conditions and the relatives assisting them, as well as all professionals serving them, should also be able to turn directly to resource centres in order to have access to all the necessary information, counselling and support.

5.7. Information and communication technologies

Expertise centres on chronic diseases, rehabilitation centres, health care and social services professionals should closely co-operate and exchange and disseminate relevant information. The information gathered by expertise centres could be stored in a national data base on chronic diseases could be made available on easily accessible chronic disease specific websites.

National call centres for people with chronic diseases linked to a national data base could provide useful information on methods of cure and care, self care, medication, assistive technology and refer chronic patients to professionals, specialists, and social services, etc. The opportunities of modern ICT and Internet should be exploited to empower people with chronic diseases to take more control their own lives. A personal "electronic patient dossier" for example can prevent superfluous or recurrent assessment procedures, diagnostic examinations and misunderstandings that put an extra burden on people with chronic diseases. Furthermore concerted action is needed to promote a more co-ordinated approach to involve people with chronic diseases and their relatives in the application and development of existing and new information and communication technologies.

5.8. The role of non-governmental organisations

Over the years the importance of non-governmental organisations (NGOs) has increased at local, regional, national, European and international level.

At local level, NGOs are providers of voluntary help and support (practical, emotional, legal, etc.), as well as professional services (home care, transport, etc.). In addition, NGOs play an important role in the prevention of disabilities and handicaps as well as in alleviating the consequences of chronic conditions or impairments by providing accessible information and counselling.

At national and international level, NGOs represent people with disabilities and people with chronic diseases in order to influence national parliaments and government bodies, institutions of the European Union, the Council of Europe and the United Nations. The mission of these NGOs is to ensure full access to fundamental and human rights as well as equal treatment through their active involvement in policy development and implementation. Their experience and expertise represent a valuable source of information for policy developers and decision takers at all levels.

6. Recommendations

6.1. Introduction

The Committee of Experts recommends that the governments of the member states of the Partial Agreement in the Social and Public Health Field, having due regard to their specific constitutional structures, national, regional or local circumstances, as well as economic and social conditions:

a. draw up and implement national programmes that apply in their policy, legislation and practice the general and specific principles as well as the instruments set out in the recommendations under 6.2;

b. promote the implementation and take steps towards the application of the principles and measures contained in the recommendations, in fields were these are not the direct responsibility of governments but where public authorities have a certain power or play a role;

c. ensure the widest possible dissemination of these recommendations among all parties concerned, particularly public authorities and professionals;

d. follow up the implementation of the provisions contained in the recommendations by all appropriate means.

6.2. Recommendations on the prevention of disabilities linked to chronic diseases

1. *Protection of human rights*

1.1. Member states have a duty to protect the human rights and fundamental freedoms of all their citizens. Consequently, they should ensure that people with potentially disabling chronic diseases are protected at least to the same extent as other citizens, in particular in respect of their right to life, human dignity and physical integrity.

1.2. Member states should guarantee full citizenship, equality of opportunity, as well as the possibility of independent living and active participation in all areas of community life for all citizens including people with potentially disabling chronic diseases.

2. *Inclusion of people with potentially disabling chronic diseases*

Arrangements for the full and effective implementation of all human rights, as enshrined in European and other international human rights instruments, must be applicable without any discrimination or distinction on any ground, including disability.

Enhancing citizenship and full participation of people with disabilities requires empowerment of the individual so that he/she can take control of his/her own life, which may require specific support measures.

People with potentially disabling chronic diseases have the right to independence, social integration and participation in the life of the community. As any other citizen, people with potentially disabling chronic diseases have the right to education, vocational training, work, protection against poverty and social exclusion, housing, protection of health as well as social and medical assistance.

Member states should combat discrimination against people with potentially disabling chronic diseases and ensure their inclusion in social and economic life.

3. *Prevention and rehabilitation*

3.1 Member states should develop primary prevention measures to prevent chronic diseases from occurring or worsening, secondary prevention measures to reduce as far as possible the degree of impairment or disability linked to a given chronic disease.

3.2 Preventive action should be taken as early as possible in the personal, occupational, environmental and social spheres.

3.3 Member states should facilitate access by people with potentially disabling chronic diseases to diagnosis, medical treatment as well as health care and social services.

3.4 Member states should ensure individualised and community based programmes of rehabilitation, including follow-up and evaluation, as well as support systems to people with potentially disabling chronic diseases and their carers and families.

4. *Measures concerning the individual*

4.1. Access to diagnosis as early as possible and its announcement accompanied with appropriate measures.

4.2. Access to information about the disease and social resources/networks.

4.3. Access to competent health care.

4.4. Access to rehabilitation measures.

4.5. Access to quality social services.

4.6. Access to adequate economic support and benefits.

4.7. Access to functional compensation solutions.

4.8. Psychological support relating to the acknowledgement and fluctuation of the disease and the uncertain life expectation.

4.9. Right to choose one's lifestyle.

5. *Measures concerning the family and carers*

5.1. Announcement of diagnosis accompanied with appropriate measures.

5.2. Health information about the disease and on the situation of the person concerned.

5.3. Promotion of the actual (voluntary) help of families, close relations, family associations or other appropriate NGOs, reinforcement of family associations, self-help groups and mutual aid associations, training of families and close relations, and promotion of their know-how and expertise.

5.4. Social resources/networks and respite/relay without negative financial consequences.

5.5. Services and support for family carers for example, respite services and reconciliation of professional and private life.

5.6. Psychological support relating to the acknowledgement and fluctuation of the disease and the uncertain life expectation.

6. *Measures concerning professionals (health care, rehabilitation, social services, education and other public administrations)*

6.1. Multidisciplinary training of professionals (continuing and up-to-date) taking into account of social and environmental dimensions of chronic diseases and of those measures that have a social impact.

6.2. Promotion of the acknowledgement of the disease.

6.3. Offering to professionals a technical datasheet relating to the disease, its treatment and the psychological support of the individual and the family.

6.4. Granting psychological support to professionals to avoid the burn-out syndrome induced by the chronic nature of the disease.

6.5. Co-ordination and exchange of information within and across health care and rehabilitation institutions and disciplines, as well as within and across public administration at all levels

6.6. Setting up professional resource centres for information and training.

6.7. Promotion of the ability to adapt interventions to the fluctuating nature of the disease.

6.8. Swift response from public administration bodies taking into account the uncertain evolvement of the disease.

6.9. Multidisciplinary and cross disciplinary approach, co-ordination and exchange of information within and across all professional levels.

7. *Measures concerning society and government*

7.1. Provision of social services for example, home help, housing services (service accommodation), institutional care, meals on wheels, transportation services, alterations of the dwelling and adding new technology.

7.2. Promotion of public awareness on the existence, impact, long-term effect, health and social consequences of chronic diseases, notably the risk of social exclusion, by regularly giving relevant thorough information.

7.3. Promotion of acknowledgement, understanding and flexibility by society at large and as early as possible, based on the principle of non-discrimination on the grounds of disease and/or disability, taking into account that:

- the evolvement of the disease fluctuates,
- the diseases or disability may not be visible,
- the diseases can be life threatening.

7.4. Providing and enhancing access to the built environment, transport, assistive technology, health care, rehabilitation, (adaptable) housing, education, employment, information and leisure activities (including culture and sport). This can be achieved through for example standardisation, harmonisation and Universal Design.

7.5. Reinforcement and extension of professional home care, including help in professional and social integration, in order to enable the person with a disability to choose his/her care setting, and to prevent and/or delay institutional care as much and as long as possible, if he/she so wishes.

7.6. Development of neighbourhood facilities for the co-ordination of care and services at all levels, notably by using an interdisciplinary approach in the field of health care and services at community level.

Appendix 1 – Definitions of disability

Definitions ICIDH

International Classification of Impairments, Disabilities, and Handicaps (ICIDH), WHO, 1980

Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.

Definitions ICF

International Classification of Functioning, Disability and Health (ICF), WHO, 2001

Impairment: a problem in body function or structure such as significant deviation or loss. (Body functions are the physiological functions of body systems, including psychological functions. Body structures are anatomical parts of the body such as organs, limbs and their components.)
(Positive aspect: *body function*)

Activity limitation:* a difficulty an individual may have in executing activities. (Activity is the execution of a task or action by an individual.)
(Positive aspect: *activity*)

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* Activity limitation replaces the «disability» used in the 1980 version of the ICIDH.

*Participation restriction**:* a problem an individual may experience in involvement in life situations. (Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.)
(Positive aspect: *participation*)

ICF 2001

Disability is conceptualised as being a multi-dimensional experience for the person involved. There may be effects on organs or body parts, for example impairment of the structure and/or function of the ear. There may be effects on certain activities such as understanding and producing messages. There may be effects on a person's participation in areas of human life such as education and work or leisure; participation may be facilitated in various ways, for instance by the provision of assistive technology or sign language interpretation.

Correspondingly, three components of disability are recognised in the ICF: body structure and function (and impairment thereof); activity (and activity limitations); and participation (and participation restriction). The classification also explicitly recognises the role of physical and social environmental factors in affecting disability outcomes.

Disability arises when any or all of the negative outcomes occur – impairment, activity limitation and/or participation restriction – when they are associated with a related "health condition"[1]; while restrictions in participation may occur for reasons other than a health-related condition, these restrictions are not considered to be included in the scope of "disability". In the WHO Family of International Classifications, health conditions are

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** Participation restriction replaces the «handicap» used in the 1980 version of the ICIDH.

[1] "A health condition is an alteration or attribute of the health state of an individual that may lead to distress, interference with daily activities, or contact with health services; it may be a disease (acute or chronic), disorder, injury or trauma, or reflect other health-related states such as pregnancy, ageing, stress, congenital anomaly or genetic predisposition" (WHO, 1999).

classified in the International Classification of Diseases, Tenth Revision (ICD-10).

See p. 24 for a diagram of the model of disability that is the basis for ICF and a chart indicating how the different levels of disability are linked to three different levels of intervention.

	Intervention	**Prevention**
Health condition	Medical treatment / care Medication	Health promotion Nutrition Immunization
Impairment	Medical treatment / care Medication Surgery	Prevention of the Development of further Activity limitations
Activity limitation	Assistive devices Personal assistance Rehabilitation therapy	Preventative rehabilitation Prevention of the development of participation restrictions
Participation restriction	Accommodation Public education Anti-discrimination law Universal design	Environmental change Employment strategies Accessible services Universal design Lobbying for change

Appendix 2 – Definitions of prevention

World Health Organization (WHO)

WHO publication 1995

In WHO's document "Disability prevention and rehabilitation in primary health care – a guide for district health and rehabilitation managers" (1995), the terms primary, secondary and tertiary prevention of disabilities are clarified as follows.

Primary prevention consists of measures to prevent diseases, injuries, or conditions that can result in impairments or disabilities. Such measures include health education, immunisation, maternal and child health services, and safety promotion. Together they comprise a major component of primary health care. District-level health care personnel are familiar with most primary prevention measures, although they may not have analysed which of these are particularly important in disability prevention.

Secondary prevention consists of early intervention in the treatment of diseases, injuries, or conditions to prevent the development of impairments. Treatment of diseases (such as tuberculosis, onchocerciasis and diabetes) and injuries (such as burns or fractures) may prevent impairments and hence disabilities. Treatment of this type is usually initiated by the referral services, but follow-up is provided within the public health care system. As with primary prevention, the health care staff may not have analysed which treatments are particularly related to disability prevention.

Tertiary prevention includes all measures to limit or reduce impairments or disabilities. It includes, for example, surgery to correct joint deformities and the provision of eye glasses for visual impairments or hearing aids for hearing impairments. In many instances, the treatment will reduce the impairment, as in the surgical correction of deformities. It may also reduce or even eliminate the disabilities that can result from impairments. Tertiary prevention also includes the treatment of disabilities, or rehabilitation. Rehabilitation is the process whereby disability is minimised or eliminated. The rehabilitation process may include training in self-care, communication, or mobility. It may also include training to develop work skills.

WHO publication 1996

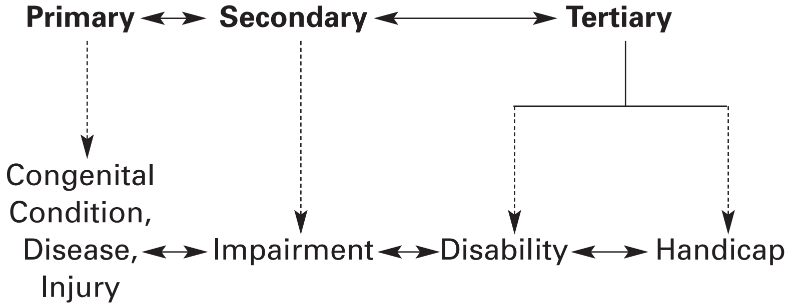
In WHO's document "Disability prevention and rehabilitation – a guide for strengthening the basic nursing curriculum" (1996), the terms primary, secondary and tertiary prevention of disabilities are defined as follows.

Primary prevention: measures which prevent diseases, injuries or congenital conditions which can result in disabilities.

Secondary prevention: treatments used for diseases, injuries or conditions which could cause impairments.

Tertiary prevention: all measures aimed at the reduction or elimination of impairments, disabilities and handicaps.

The relationship between the levels of prevention and the occurrence of impairments, disabilities and handicaps is illustrated below:



According to the WHO, rehabilitation is generally considered to be the component of tertiary prevention which focuses on the reduction or elimination of a disability. Measures used to assist people with disabilities to improve their abilities in activities such as self-care, communication, moving around, behaving according to social norms or developing vocational skills, are generally considered to be rehabilitative measures.

United Nations

The following definitions are developed from the perspective in the World Programme of Action Concerning Disabled Persons:

Prevention is any measures aimed at preventing the onset of mental, physical and sensory impairments (primary prevention) or at preventing impairment, when it has occurred, from having negative physical, psychological and social consequences (secondary prevention). Prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunisation campaigns against communicable diseases, measures to control endemic diseases, safety regulations, programmes for the prevention of accidents in different environments, including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Rehabilitation is a goal-oriented and time-limited process aimed at enabling an impaired person to reach the optimum mental, physical and/or social functional level, thus providing the individual with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example, by technical aids) and other measures intended to facilitate social adjustment or readjustment.

Equalisation of opportunities is the process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all.

Prevention and rehabilitation, then, relate to an individual's particular attributes (or lack thereof) and may entail special needs. Equalisation relates to the process of building a suitable environment to reasonably accommodate those needs.

Council of Europe

In Recommendation No. R (92) 6 of the Committee of Ministers to member states on a coherent policy for people with disabilities, the Council of Europe defines prevention threefold:

1. Prevention of impairment: to prevent an impairment from arising or worsening.
2. Prevention of disability: to reduce as far as possible the degree of disability for a given impairment.
3. Prevention of handicap: to reduce any social disadvantage arising from a given disability.

Recommendation No. R (92) 6 includes the definitions of "impairment", "disability" and "handicap" as established in the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published by the World Health Organization in 1980.

According to the Council of Europe report on Use and usefulness of the ICIDH for policy and planning of public authorities (1995), the use of the ICIDH for policy is particularly meaningful when used to formulate prevention-focused policy. ICIDH-based prevention policy gives a good opportunity to evaluate the effect of policy measures. The report recommends that the formulation of rehabilitation policy objectives in terms of prevention-stimulating measures, thus showing that the government has a task in:

- preventing an impairment from arising or worsening;
- preventing disabilities from arising or worsening;
- preventing social disadvantages/handicaps from arising or worsening.

The report recommends furthermore that the relevant public authorities of member states be encouraged to formulate their policy in the way outlined above.

Recommendation No. R (92) 6 recommends the following preventive measures.

Prevention of impairment

To act against direct or indirect causes of impairments:

- action for the prevention of accidents (occurring, for instance, in the home, on the roads, on the sports field, at school and at work);
- action for the prevention of diseases (including occupational diseases, diseases associated with leisure activities, diseases common with elderly people, etc.).

This action should comprise monitoring at various stages during the period of growth, regular check-ups for workers at risk, immunisation, and monitoring of degenerative diseases.

To prevent congenital impairments, services should be set up to provide genetic screening;

- pre-marital screening and diagnosis;
- monitoring of high-risk and normal pregnancies and confinements;
- care for high-risk new-born babies;
- early detection and diagnosis of diseases as well as mental, motor and sensory disorders.

Prevention of disability

In addition to the measures to detect, treat and diagnose impairments at an early stage:

- individualised and community programmes of rehabilitation, including follow-up and evaluation;
- support to individuals and their families.

Prevention of handicap

Along with the steps recommended to prevent impairment and/or disability:

- individualised programmes of psycho-social rehabilitation aiming at the full development of the person;
- provision of information, so as to promote the full integration of people with disabilities into society.

Health education

Educational action intended to prevent impairment should be aimed at the whole population, and primarily at young people of school age, i.e. at a time when children from all backgrounds are still particularly open and amenable to the reception of simple but effective messages concerning health education. Action in regard to specific problems should be aimed at certain specific groups such as women of child-bearing age, couples, drivers and the elderly. Consequently, the information which has to be given should relate to factors and circumstances which may give rise to impairment.

Where there is an impairment, health education may be useful to prevent or limit a disability. The educational action should be aimed at the people suffering from the impairment, their families and all those – the general public as well as professional staff – who may be concerned.

Health education directed to prevent impairments or disabilities from becoming handicaps extends to the whole of society and may promote the concepts of integration and rehabilitation, of equality of opportunity and of participation for people with disabilities.

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